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ABSTRACT

Major research findings are synthesized and innovations of current concern to vocational rehabilitation professionals are reported in this document, which covers the area of independent living. Independent living is described as an integral part of the rehabilitation process for the severely disabled in which the individual is assisted in achieving personal and vocational objectives. In the introductory chapter, three partial concepts of independent living are reviewed: physical modification, rehabilitation, and consumer rights. Chapter 2, concerning independent living and federal rehabilitation legislation, reviews attempts to introduce independent living as a component of vocational rehabilitation services, illustrating a number of planning issues that confront policy makers. Chapter 3 discusses the problem of defining the target populations. Chapter 4 describes alternative delivery strategies/systems for independent living services, identifies several major dimensions of these programs, and reviews several examples of independent living service models. Chapter 5 reviews two programs where alternatives for organization and delivery of independent living services are being systematically evaluated. Chapter 6 reviews analytical and theoretical work to date on estimating the costs and benefits of independent living. Chapter 7, the conclusion, re-emphasizes the main programmatic features of the consumer model of independent living, and outlines major policy questions and the agenda for exploring new alternatives. An annotated bibliography is appended. (TA)

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EMERGING ISSUES IN REHABILITATION

Institute for Research Utilization
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Washington, D.C. 20024

INDEPENDENT LIVING

by

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EMERGING ISSUES IN REHABILITATION

AN INTRODUCTION TO THE SERIES

The four comprehensive papers in the EMERGING ISSUES IN REHABILITATION series synthesize major research findings and report on innovations of current concern to vocational rehabilitation professionals:

Independent Living
by Susan Pflueger, with a Foreword by Edward V. Roberts
New Directions in Rehabilitation Outcome Measurement
by Thomas E. Backer, Ph.D.
Perspectives on National Health Insurance and Rehabilitation
by Herbert Dorken, Ph.D., with a Commentary by Joseph LaRocca
Sheltered Industrial Employment
by Carolyn L. Vash, Ph.D.

The Rehabilitation Services Administration Research and Evaluation program (DHEW) has long sought to promote the utilization of research results in order to improve the efficiency and effectiveness of vocational rehabilitation programs. In keeping with that effort, RSA made a grant to the Institute for Research Utilization to identify, select, and summarize the literature in selected areas of urgent concern to the vocational rehabilitation (VR) community. The Grant, Number 22-P-5901 9/3-01, was entitled "Literature Review on Topics of Urgent RSA Need and Concern."

To help ensure the selection of topics relevant to the VR field, the project staff convened a Consumer Panel of representatives of potential user groups: counselors, supervisors, State VR administrators, and planners and policymakers. The panel members nominated, discussed, then ranked in order of urgency, topics which they felt would be desirable for the literature reviews. They also recommended potential subject experts for each topic.

Many rehabilitation practitioners and administrators lack the time to keep up with research developments. They want to know *what* works in a given situation, and *how* to make it work. To facilitate this, each paper was prepared for a specific audience, and written in a clear, readable style. Annotated bibliographies accompany each report.

ELIZABETH L. PAN, PH.D., PRINCIPAL INVESTIGATOR

JUDITH J. SENKEVITCH, PROJECT MANAGER

DECEMBER 1977

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FOREWORD

In its broadest implications the independent living movement is the civil rights movement of millions of Americans with disabilities. It is the wave of protest against segregation and discrimination and an affirmation of the right and ability of disabled persons to share fully in the responsibilities and joys of our society.

The movement's strength comes from the fact that it represents all people with special needs--the aged, the physically disabled, the developmentally disabled, and the mentally ill. At no time was this more apparent than during the Section 504 demonstrations in April, 1977. At that time, people of all different disabilities joined hands and demanded their full human and civil rights as equal Americans. This demonstration capped a series of efforts by the general public and legislators to achieve laws and guidelines that would open the doors to education, employment, housing, transportation and recreation for people with special needs.

Medical and rehabilitation technology has made tremendous advances in the last few decades and we are now able to help persons with even the most severe disabilities to the point of independence. The problem we now face is how to make changes in our environment so that these persons can complete the rehabilitation process and become actively participating and valued members of our communities.

The independent living movement has made all of us aware of our society's underdevelopment and the scarcity of resources available for people with special needs. As I learned from personal experience as a post-polio respiratory quadriplegic, a disability is a condition that usually can be stabilized and assimilated into one's self image, but a handicap is a condition that is created by the service gaps and architectural and attitudinal barriers in society. It's the handicap that is so limiting. We can, by focusing our efforts on the development of society's capability to accommodate and sustain people with special needs, cause that handicap to disappear. It's important to realize that disability can happen to anyone and that there are literally hundreds of thousands of people in this country who, because of age, disability or other factors, are now denied the chance to lead a full and active life because of the underdevelopment of our communities and social service systems.

I believe that the basic premise of the independent living movement is that everyone has potential to live more independently. Our experience shows that even the most severely and profoundly disabled individual can be independent--they may need all kinds of help --but that they can be in control of their lives.

Today, our vocational rehabilitation system addresses only a part of the overall need of the individual and serves those most easy to rehabilitate. As we attempt to carry out the mandate of the Rehabilitation Act of 1973, which requires state rehabilitation

agencies to serve people with severe disabilities as a first priority, we are becoming increasingly aware of the gaps that exist in our programs and the lack of community services. We are realizing that our programs tend to systematically reject the people with the greatest needs. Many people with severe disabilities need extensive independent living and pre-vocational services in order to be helped by our vocational programs and once they complete our programs, they continue to need independent living services to varying degrees for the rest of their lives. For the most part these services do not exist in our communities. This review focuses on independent living services and the new self-help programs that have emerged to provide these services, and advocacy for people with severe disabilities. It also discusses the importance of these organizations to our rehabilitation system and the continuing improvement of the system's ability to serve people with even the most severe disabilities.

The largest and best known of the independent living programs is the Center for Independent Living (CIL) in Berkeley, which in its six years of operation has had a major effect on the accessibility and responsiveness of the Bay Area community and the ability of that community's residents to live more independently. CIL was started by a group of people with severe disabilities who came from an experiential base and felt a strong dissatisfaction with the institutional network that society had set up to help them. I was one of the founding members. One of the keys to CIL's success was that our dissatisfaction with the existing level of services was shared by many people in the helping professions, government and the general public, and that those who were receptive to CIL's ideas and goals lent their support in terms of energy, commitment and dollars to the development of CIL's programs. As a result of this support we were able to develop an innovative concept into an important link in our medical/rehabilitation system.

Organizations such as CIL fill a major gap in our medical/rehabilitation network. Their focus is on integration and the services needed to move people into the mainstream. Independent living programs deal with the quality of life people lead in the communities; they are service and training centers, but primarily they are advocates working to develop a public awareness of the needs and capabilities of people with severe disabilities, as well as an awareness within the disabled individual of his potential for a life of greater participation and involvement.

In California, the State Department of Rehabilitation has in the past year used its new Innovation and Expansion (I&E) Grant capability to stimulate the development of independent living programs throughout the state. Currently there are 14 of these organizations in California, nine of which were started by I&E grants. We regard these programs as essential components in the network of community-based services. The programs help clients move toward vocational goals and are valuable resources in developing in employers, helping professionals, and the general public a greater awareness of the employment and independent living potential of all people with disabilities. We anticipate that these programs will help the department reach out to the many people who have been excluded from

Department of Rehabilitation programs for reasons of severity of disability, and that they will function as important resources for supportive services, counseling, pre-vocational and vocational training throughout the rehabilitation process.

California is not the only state that has done this. State rehabilitation agencies in Michigan, Massachusetts and others have also begun to facilitate development of independent living programs in their communities. This trend has gone hand in hand with the growing conviction of state rehabilitation agencies that they can and should serve a wider range of clients--including those people who, for many reasons, do not have an employment goal, but who can be helped significantly toward greater independence and integration. It is significant that at a recent meeting of the Council of State Administrators of Vocational Rehabilitation (CSAVR), 88% of the state directors felt that independent living services should be a part of state rehabilitation programs. A few years ago only a few state directors felt that way.

In coming months Congress will be considering allocating funds for the establishment of independent living programs throughout the country. It will also be considering expanding the mandate of state rehabilitation programs to enable them to serve people who do not have vocational goals. Both pieces of legislation are immensely important, but they are not the total answer. Any comprehensive service system for people with severe disabilities must include a range of in-home supportive services similar to the California Homemaker/Chore program which provides funds for people to hire and train their own attendants. A program such as this provides a real alternative to institutionalization for many people and provides them with the opportunity to become part of the mainstream. Making independent living a reality for people with severe disabilities is not the sole responsibility of rehabilitation. It's a responsibility shared by all government programs, the general public, business and industry, and private service agencies. We need to work together to build a complementary social system in this country, one that makes it possible for people with special needs to live as equal citizens.

Edward V. Roberts

Edward V. Roberts, Director
California Department of Rehabilitation

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This review has been, from the beginning, a team project. Ed Roberts, Director of the California Department of Rehabilitation, is one of the most prominent leaders in the Independent Living Movement, and it was Ed who contacted me and invited me to work on the review. Throughout the planning and writing, Ed and his Administrative Assistant, Joan Leon, have contributed time and ideas, and have shared the tensions of publishing deadlines. Ed has been the principal editor of this paper. Ed also has been the creative force behind many of the ideas that have manifested themselves in the independent living programs described in these pages.

Judy Senkevitch, of the Institute for Research Utilization, was Project Director. Judy and her staff provided bibliographic materials and were responsible for final production. Bruce Schmidt, as research assistant, prepared many of the background materials used in the review. The Center for Independent Living (CIL), Berkeley, provided transcripts from the 1975 Independent Living Conference, as well as literature materials from their review role in the Comprehensive Needs Study conducted by the Urban Institute.

Fred Fay, Lex Frieden, Don Galloway, and Judy Heumann, as subject experts, provided constructive feedback on earlier drafts, and wrote sections of this review, on their own programs and experiences in independent living. Dr. Herb Liebowitz, Rehabilitation Services Administration (RSA), reviewed and commented on early drafts. Elizabeth Pan, Principal Investigator, designed the process by which independent living was selected as a review topic. Liz also arranged and conducted an authors' conference, where I was fortunate to meet and share ideas with the other authors of reviews in this series: Tom Backer, Carolyn Vash, and Herb Dorken, as well as Bert Griffis of RSA. Berkeley Planning Associates provided space and use of their extensive rehabilitation library for Bruce, Joan and myself.

Susan Pflueger
Berkeley, California and The Tabard
Inn, Washington, D.C.
October, 1977

I. INTRODUCTION

> To us, independence does not mean doing things physically alone. It means being able to make independent decisions. It is a mind process not contingent upon a 'normal' body.
>
> Judy Heumann, Center for Independent Living, Berkeley, California
> August, 1977

"Independent Living" for persons with severe physical disability is an important rehabilitation concept in the 1970's. The concept is new, and constantly developing. It is not surprising then, that the definition of independent living is unclear to many. Depending on one's point of view and background in rehabilitation, the term "independent living" may imply various levels of services and programmatic intent. In October 1975, the first national conference on the State of the Art in Independent Living was held in Berkeley, California. The conference was organized by the Center for Independent Living (CIL), Berkeley, and made possible through a grant from the Rehabilitation Services Administration (RSA). Leaders in vocational rehabilitation and individuals in the independent living consumer movement met and exchanged ideas. A number of participants in the conference were surprised with this new concept emerging around the country.

When those active in the disabled movement use the term "independent living," they are referring to their ability to actively participate in society--to work, have a home, raise a family, and generally share in the joys and responsibilities of community life. They are referring to the human services necessary to reduce barriers to such community participation. As articulated in that Berkeley conference in 1975, independent living is an integral part of the rehabilitation process for the severely disabled, an essential component of a program that hopes to help people with severe disabilities achieve their personal and vocational objectives. This is a new definition of independent living which has developed from three previous independent living concepts that in themselves provided partial and limited solutions for the individual with a severe disability. Before discussing the implications of this new, more comprehensive definition, it is helpful to review the three partial concepts--physical modification, rehabilitation, and consumer rights.

Three Partial Concepts of Independent Living

Physical Modification (Aids to Daily Living)

First is the traditional concept of independent living services as aids to daily living--the wheelchairs, orthopedic devices, special equipment, and housing modifications that permit people with severe physical disabilities to care, somewhat, for their own survival needs.

The focus of this concept is modification of the physical environment to make accomplishment of activities of daily living more feasible. Physical modification may satisfy basic survival needs of these individuals, and concern with such needs is the basis for some important new programs established with the title "independent living." For example, the US Department of Housing and Urban Development (HUD) has established a new Office of Independent Living with a concern for special housing. The focus on physical modification is a crucial but still only partial answer to the needs of individuals with severe disabilities.

Independent Living Rehabilitation (ILR)

A second concept of independent living had developed in drafts of vocational rehabilitation bills. Vocational rehabilitation services are available to handicapped individuals for whom vocational objectives are feasible. Many have argued that, for these individuals, a separate program could provide services without respect to vocational objectives. With this intent came recommendations that such an "independent living program" be administered separately from vocational rehabilitation. In other words, this idea assumed a clear distinction between those individuals in need of independent living services (vocationally "non-feasible") and individuals for whom vocational goals are feasible. For the "non-feasible," a separate independent living service system was advocated. By definition, this concept of independent living as distinct from vocationally oriented services may preclude vocational goals for the individual with severe disability.

Consumer Rights

A third concept developing at the same time focused on attitudes and on the rights of people with disabilities. The independent living movement includes consumers and professionals, advocating change in general attitudes and provision of the services that individuals with disabilities need in order to take part in community life. While the first two concepts are essentially programmatic in nature, the independent living movement has not been restricted to any one program or service system, but has advocated an integrated service system focused on the services needed to help people be independent. The concept enhances the belief that people with disabilities have the right to services that enable them to be equal and independent members of the community.

Comprehensive Definition

The development of a comprehensive definition of independent living has been recent, and is still going on. The ideas from these three previous independent living models are to a great extent complementary, although each in itself might be viewed as incomplete. The independent living movement has provided impetus for changes in programmatic approaches to independent living.

Housing: For example, the concept of housing for the disabled is changing in HUD from large, segregated and institutional housing projects to a range of housing alternatives that provide varying degrees of services and control depending on needs of residents. There is a new commitment to the least restrictive and most integrative environments, compatible with the goals of the independent living movement.

Rehabilitation: Since the Rehabilitation Act of 1973 called for priority to the individuals with most severe handicaps, vocational rehabilitation professionals have gained new experience in the independent living needs of their clients. Vocational rehabilitation professionals are now more aware that independent living services are often needed by individuals with severe disability in connection with the vocational rehabilitation process, and may be needed before, during, and after "rehabilitation." Independent living services may be necessary in order to compensate for the fact that many severely disabled individuals have not gained skills needed to be independent, nor had the opportunity to develop motivation toward vocational goals. Vocatonal rehabilitation counselors are finding that independent living need not be a parallel and separate system, but can complement vocational rehabilitation objectives.

While the independent living movement has brought about some changes in how major programs view service need, the emphasis has not been entirely on defining for government agencies an exclusive role in provision of independent living services. Alternative, consumer-run organizations ("centers for independent living") have developed both to coordinate and complement services provided by government. These centers, which will be described in more detail in Chapter IV of this paper, are organizations which are based on the new meaning of independent living that has developed, combining physical modification services, rehabilitation, and consumer rights into a comprehensive network of service for the person with a severe disability. The goal is a network that provides a continuum of services from the point of disability (onset of disability at whatever age) throughout the person's lifetime--a continuum that can include opportunities for vocational rehabilitation services. Focus in this model is on the individual, rather than the program. In this context, vocational education and vocational rehabilitation services may be utilized by the individual as he gains the ability to benefit from them and as he develops the self-direction needed to choose a life goal. The diagram below, Figure I, illustrates the relationship between the individual with a disability, the family, established service systems such as state rehabilitation agencies, and the many distinct "independent living" services that make up the comprehensive rehabilitation package. The diagram was created in 1975 by Ed Roberts and the staff from CIL, Berkeley, working with Dr. Herb Liebowitz, of RSA, Region IX, for the Conference on Independent Living.

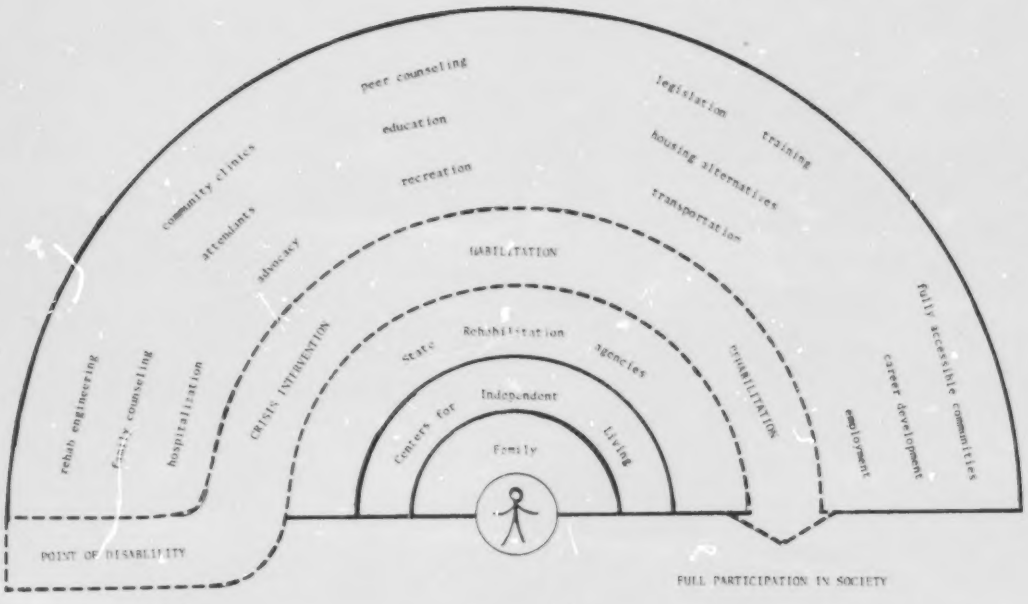

FIGURE 1

The continuum is made up of a complementary network of services provided both publicly and privately. The services needed at the time of crisis intervention (diagnosis or onset of disability) include peer counseling, family counseling, medical care, rehabilitation engineering (equipment and prostheses). This crisis intervention period usually is defined as the time the individual is undergoing major medical care leading to the treatment and the stabilization of health. As the individual gains the ability to leave a hospital environment, a second period called "habilitation" comes into play--this is the period during which primary emphasis is on personal adjustment to disability and on increasing independence and self reliance.

During habilitation, appropriate housing alternatives are critical--historically, a great many people with severe disabilities moved from hospital environments to nursing homes and other care institutions. There now are new alternatives that facilitate the development of independence and a positive self-image. (Cole and Frieden, 1976)

It is during this period that the independent living centers can play a critical role through the provision of life-support services and peer counseling, and also when vocational rehabilitation programs may begin to support the career development of the individual. The length of time necessary for the habilitation phase varies in time depending on the individual and on the community environment. Clients in new independent living programs have achieved habilitation in less than a year while previously, without independent living programs and services, the process might take five years if habilitation was achieved at all.

The next stage we defined as rehabilitation, the period of development of a definite lifestyle and career objective, which could range from homemaker, part time and intermittent employment to full time employment in the primary labor market. The work aspect of the continuum is critically important because it is only through work and other productive activities that an individual really becomes a part of the mainstream, a valued member of the community. Therefore, to the extent that an individual chooses and can attain a vocational objective, these objectives are an integral part of the independent living process.

The diagram shows an end to the individual's process as "point of full participation." This does not mean, however, the end of independent living services, if ongoing services are necessary for active participation. Such services as attendant care and peer counseling may always be important as support services for the independent person with severe disability.

What is described here is a flexible and supportive system, a system that provides opportunities and choices for the individual with a severe disability, development of his or her lifestyle and career.

As we have seen, there have been several distinct developments related to independent living for the disabled. First, a traditional emphasis on housing and aids to independent living that focused on modifications making life tasks and self-care easier for the severely disabled. Second, a programmatic concept in vocational rehabilitation that viewed independent living as separate from vocational rehabilitation programs, and for those without vocational objectives. Thirdly, the focus in the Independent Living Movement on client rights and advocacy, filling service gaps, and breaking down attitudinal barriers.

These three concepts formed the basis for what has developed, and is still developing, as <u>independent living</u> exemplified in many independent living consumer organizations around the country. <u>Independent living</u> has six basic elements:

- <u>Focus on the individual</u> with disability, and maximization of that individual's opportunity for participation in society.

- Provision of the services needed by that individual, either through established service organizations such as vocational rehabilitation or housing programs, or through independent living centers that integrate a variety of public and private services available in the community, and provide other services not available elsewhere.

- Focus on choice for the individual, on alternative ways that housing and service needs might be met.

- Integration of an individual's need for support services and achievement of "habilitation" or a living situation that works, with life goals such as vocational and educational objectives.

- Provision of both "crisis" or intervention services related to the onset of disability, and on-going services that support stabilization and individual development during and after "rehabilitation."

- Advocacy of the rights of individuals with disability.

Scope and purpose

The chapters of this review cover a number of important issues and programs related to the provision of independent living services.

Chapter II, on "Independent Living and Federal Rehabilitation Legislation," reviews attempts to introduce independent living as a component of vocational rehabilitation services, illustrating a number of planning issues that still confront policy makers:

- What are the service needs related to independent living?

- Who should be served?

- How should an independent living program be administered?

- How should independent living rehabilitation relate to vocational rehabilitation?

- How much would an independent living program cost?

The legislative review traces independent living proposals from 1959 through the veto of the 1972 Rehabilitation Act, to the 1973 Act with its priority on serving the severely disabled, and more recent legislation impacting this group.

Chapter III discusses the problem of "Defining the Target Population." There have been inconsistencies in the use of definitional terms: "impairment," "disability," "handicap," and "severity." In addition, there are a number of alternative measures of "severity."

Implementation of the Rehabilitation Act of 1973 has obviously been affected by these definitional and measurement difficulties. (Barrett, 1975). Estimates of need for independent living services were made during the Comprehensive Needs Study authorized by Congress as part of the Rehabilitation Act of 1973.

Chapter IV describes "Alternative Delivery Strategies" for independent living services. The centers for independent living that have emerged throughout the country provide, for the disabled, linkages with services and funding upon which they depend in order to live in the community. Several major dimensions of these programs are identified:

- Services provided in a non-residential setting versus services in a residential model
- Services provided directly versus services provided by referral to community services
- Population served: one disability group versus integrated group
- Professional base versus consumer base
- Vocational versus non-vocational service plan objectives
- Transitional versus permanent on-going services.

Several examples of independent living service models are reviewed:

- Center for Independent Living (CIL) Berkeley, California
- New Options, Houston, Texas
- Boston Center for Independent Living (BCIL)
- Atlantis, Denver, Colorado
- Campus living programs

Chapter V reviews two important programs where alternatives for organization and delivery of independent living services are being systematically evaluated:

- The Section 130 Demonstration Projects authorized by the Rehabilitation Act of 1973 as a part of the Comprehensive Needs Study.
- The use of I&E funds for independent living programs, particularly in California.

Chapter VI reviews analytical and theoretical work to date on estimating the costs and benefits of independent living. Traditional economic justification of vocational rehabilitation services for the disabled has rested on the program's focus on gainful employment. Even if the legislative mandate were to be expanded to permit independent living closures, difficulty in defining independent living gain presents a major obstacle in economic analysis. Some preliminary estimates of program cost are reviewed. Benefits are discussed in terms of estimation of an individual's non-income gain, reduction of costs of institutionalization, and support for gainful employment.

Chapter VII, the conclusion, reemphasizes the main programmatic features of the consumer model of independent living, and outlines major policy questions and the agenda for exploration of new alternatives.

Following the conclusion are two important sections. The first is a report on current regional and local program developments prepared for this paper by nationally recognized leaders in the independent living movement: Ed Roberts, Fred Fay, Lex Frieden, Don Galloway, and Judy Heumann. The second, prepared for the BCIL Report, is a "Checklist for Developing Independent Living Projects." An annotated bibliography is appended.

This paper has been prepared to inform vocational rehabilitation counselors, planners, and administrators of the major issues and programs in independent living. The new concept of independent living combines physical modification, rehabilitation, and client rights--and is not limited to one of these ideas. The combination of these three aspects is important for expression of individual choice of services and living alternatives. The concept of choice, of independent decision, is extremely important to any individual. Yet with institutional care arrangements and restrictive limited societal expectations, self-determination has often been denied to the severely handicapped. "Independent living" means the opportunity for such expression.

Implications of the Independent Living Concept for Other Groups

The programs reported in these pages have been primarily designed for persons with severe physical disability. However, there are a number of service needs that are common not only to the physically disabled, but to other handicapped individuals, such as the elderly and the mentally retarded. The independent living movement started as a coalition of physically disabled, but is gradually expanding to provide services for other groups. The programs and the philosophy developed in the centers for independent living are relevant. The emphasis on coordinated services focused on individual need makes this a universal model for developmentally disabled, the elderly, the mentally ill and others with handicaps that restrict individual ability to live independently.

II. INDEPENDENT LIVING AND FEDERAL REHABILITATION LEGISLATION*

A review of the legislative history of vocational rehabilitation program funding shows Congressional concern for independent living as a part of vocational rehabilitation legislative process dating back to 1959. This brief review of attempts to introduce independent living as a component of vocational rehabilitation services illustrates a number of planning issues that currently confront the policy maker:

- What are the service needs related to independent living?
- Who should be served?
- How should an independent living program be administered?
- How should independent living rehabilitation relate to vocational rehabilitation?
- How much would an independent living program cost?

1959-1971

Vocational rehabilitation legislation dates back as far as 1920, when the original Smith-Fess Act, P.L. 66-236, authorized training, counseling, and placement services for the physically handicapped, related to vocational goals. However, it was not until 1959 that independent living rehabilitation services were proposed in Congress. In that year, two bills, HR 361 and HR 5416, contained titles relating to "independent living rehabilitation services." Emphasis in this early bill, however, was on reduction of the public burden by reducing a disabled person's need for an attendant, and increasing "ability of independent living."

Bills of similar spirit were introduced in 1961 containing titles on "Independent Living Rehabilitation Services." These called for a cooperative arrangement between the state agencies to provide independent living and those ancillary social services needed for independent living. The intent was to establish a separate program for independent living. The authors, primarily the National Rehabilitation Association (NRA), indicated that due to lack of administrative experience in the area of independent living, two programs should exist. "This arrangement will assure that attention given to the new program will not detract from emphasis on vocational rehabilitation" (Urban Institute, 1975).

The administration opposed these provisions. Indecision on the part of the Department of Health, Education and Welfare (HEW) in designating who was to administer the provision--public health, rehabilitation, or social services--has been cited as the ultimate cause of failure (Urban Institute, 1975, p. 8). Even though "independent living rehabilitation" legislation failed, a number of programmatic

*This legislative review draws heavily from the reviews included in the Report of the Comprehensive Service Needs Study (The Urban Institute, 1975) and in Barrett (1975).

gains affecting the ability of disabled individuals to obtain services and dollars and to make changes in the environment were achieved in rehabilitation, mass transit, Social Security, and Medicare legislation during this period. Money for attendants and for health care became more available to the disabled through other state and federal social programs. And in 1972, rehabilitation bills greatly expanding the concept of independent living services to the severely disabled were written.

1972

In 1972 HR 8395--written as a new Act to replace the Vocational Rehabilitation Act (scheduled to expire June 30, 1972)--outlined a considerably expanded mandate for vocational rehabilitation, including comprehensive services to the severely handicapped. "Severely handicapped" were defined as: (1) having a physical or mental disability so serious that it limited substantially the ability to function in the family and community as one without such a serious disability may be expected to function; and (2) who, with the assistance of comprehensive rehabilitation services, can reasonably be expected to improve substantially the ability to live independently and function normally in the family and community (Barrett, Addendum, p. 5).*

Senate hearings considered a number of bills on the handicapped, including HR 8395 as reported out of the House committee. Emphasis on the severely handicapped gained momentum in the Senate subcommittee hearings. Not only were supplementary funds approved to provide comprehensive rehabilitation services for the severely handicapped without vocational objectives, but priority service to the severely handicapped was provided in the basic vocational rehabilitation program as well.

HR 8395 was reported out of conference on October 11, 1972 with no dissenting votes. Senator Alan Cranston, as Chairman of the conference committee, stated "the crucial thrust of the conference report Title I program is to eliminate the creaming and shift the focus to harder cases in order to serve individuals with more severe handicaps."*

Definitions in the bill are of particular interest. "Comprehensive rehabilitation services" meant vocational rehabilitation services and any other goods (including aids or devices) or services provided with funds under titles of the Act that will make a substantial contribution in helping a handicapped individual to improve his ability to live independently or function normally with his family and community (Barrett, 1975, p. 13).

"Handicapped individual" meant any individual who: (a) has a physical or mental disability which for such individual constitutes or results in a substantial handicap to employment; and (b) can reasonably be expected to benefit from vocational rehabilitation services or comprehensive rehabilitation services.

* A detailed review of the legislative history of the ill-fated 1972 bill, as well as the 1973 Act, can be found in Barrett, Linda, Legislative Review, Berkeley Planning Associates, September 1975.

"Rehabilitation," for purposes of Title II of the bill, meant the goal of achieving, through the provision of comprehensive rehabilitation services, substantial improvement in the ability to live independently or function normally with the family or community on the part of the handicapped individual who was not capable of achieving a vocational goal at the present time. (Barrett, 1975, p. 15).

The report on HR 8395 was agreed to unanimously by the Senate and House and presented for approval on October 14, 1972. President Nixon announced his pocket-veto on October 27, 1972. President Nixon's Memorandum of Disapproval stated, in part:

> This measure would seriously jeopardize the goals of the vocational rehabilitation program and is another example of Congressional fiscal irresponsibility. Its provisions would divert this program from its basic vocational objectives into activities that have no vocational element whatsoever or are essentially medical in character. In addition, it would proliferate a host of narrow categorical programs which duplicate and overlap existing authorities and programs. Such provisions serve only to dilute the resources of the vocational rehabilitation program and impair its continued valuable achievements in restoring deserving American citizens to meaningful employment. (Urban Institute, 1975, p. 9)

The vetoed bill was reconsidered by the 93rd Congress and while some changes were made, the independent living provisions were retained. Again, President Nixon vetoed the bill (in this case, S. 7).

The Rehabilitation Act of 1973

Veto of HR 8395 resulted in a continuation of the existing Vocational Rehabilitation Act through July 1973 at 1972 funding levels. In 1973, failing at the second attempt to override the Presidential veto, the House and Senate developed a compromise bill, which dropped the provisions for the new independent living comprehensive service program, but did mandate priority of service in the basic vocational rehabilitation service program to the severely disabled, and include authorization for a major study of the comprehensive needs of the severely disabled (Section 130).*

Other sections of the Rehabilitation Act of 1973 that pertain especially to the goals of community integration and independent living are Sections 501, 502, 503 and 504** which call for affirmative action programs for employment of the disabled in firms contracting with the government; provision of barrier-free work areas in such

* Included in this Comprehensive Needs Study are six demonstration projects, which are reviewed later in this paper.

** Section 504 was not implemented until May of 1977, and then only after a national demonstration by the disabled.

firms; removal of architectural and transportation barriers to the handicapped; creation of the Architectural and Transportation Barriers Compliance Board; and non-discrimination on the basis of handicap for programs and activities receiving or benefiting from federal financial assistance (Federal Register, Wednesday, May 4, 1977, part IV).

1974 to present

In 1974 the Vocational Rehabilitation Act was amended. Of particular interest in these amendments was the authorization of a White House Conference on the Handicapped, and broader definition of "handicapped individual" to focus on substantial limitations of an individual's functioning in one or more of his major life activities, rather than on handicap to employment, vocational objectives or potential benefits from vocational rehabilitation services.

Since the amendments of 1974, there has not been major vocational rehabilitation legislation pertinent to independent living definitions or expansions of vocational rehabilitation scope of services to cover independent living services. There have been other major laws that have directly affected independent living capabilities. Among them:

- Education for all Handicapped Children Act of 1975 (PL 94-142), which calls for a sharply increased federal commitment to insure that all handicapped children receive full and appropriate educational services.

- Developmentally Disabled Assistance and Bill of Rights Act (PL 94-103).

- Supplemental Security Income (SSI) amendments (among them, PL 94-566, PL 94-365, PL 94-569, and PL 94-585) extending SSI benefits to aged, blind and disabled recipients in publicly operated community residences, and a new assistance program for SSI-eligible children.

- National Housing Act Amendments of 1975 (PL 94-173), Title I, which includes provisions for the removal of barriers, hazards and inconvenient features of housing for handicapped people.

In addition to these new laws, an Office of Independent Living was established in HUD in June 1977. Secretary Harris announced the creation of the Office at the White House Conference and stated that the overall objectives of the Office are to promote the creation of independent living centers across the country and to make more and better housing available to the handicapped.

One current bill, entitled "Independent Living Program for the Handicapped Act of 1977," was introduced in 1977 by Congressman Koch (New York) and provides for experimentation with a series of projects directed at serving the severely handicapped.

A review of all major legislation benefiting the handicapped is compiled biannually by the Office for Handicapped Individuals (OHI), HEW (1974, 1975-76). For more detailed information about legislation pertaining to the handicapped, the reader is referred to these OHI summaries, or to the legislation itself. This review has highlighted the progress of the independent living concept in vocational rehabilitation legislation. There is yet much to learn about population to be served by independent living services, and the economic justification for delivery of services. In the next pages of this paper these topics are addressed separately.

III. DEFINING THE TARGET POPULATION

The Rehabilitation Act of 1973 mandated priority in services to the "severely disabled." It is the severely disabled for whom independent living services are so critical and for whom the programs discussed in this paper have been designed. Yet, there are numerous definitional issues that have impeded policy planning and program development. In this section, we will discuss major aspects of the definitional problem as it affects the planning and design of independent living services and programs. In discussing the need for independent living services, there are a number of concepts addressed in the literature on identifying the population to be served.

Definition of Terms

Most authors on independent living policies have adopted the following definitions of "disability," impairment," "severity," and "handicap":

- Impairment -- a physiological or anatomical loss or other abnormality or both.
- Disability -- the limitation on an individual's capacity to perform some key life function caused by an impairment.
- Handicap -- the limitation imposed by a disability on an individual's ability to carry on his or her usual activities.
- Severity -- the degree of impairment, disability or handicap; at the worst degree of severity, the above three terms are virtually synonymous.

These are terms as used in this review, and are consistent with materials from the Comprehensive Needs Study (Urban Institute, 1975), the HEW audit study of vocational rehabilitation services (Barrett, 1975) and others.

Measures of Severity

In mandating priority for the "severely handicapped," the 1975 Rehabilitation Act called for a definition useful for eligibility decisions and for recording type of caseload. The present system is limited to an indication on a list of diagnostic categories which automatically or with qualification mean severely disabled, including all Social Security Disability Insurance (SSDI) beneficiaries and all blind and disabled SSI recipients as severe cases, and allows for other cases on the basis of functional limitation factors and the requirement of multiple vocational service over an extended time. In general, those doing substantive work in assessing how to implement policy regarding severe cases opt for emphasis

on handicap, or the limitation imposed by a disability interacting with other variables to prevent carrying out activities. A comprehensive review of alternative approaches to the definition of severity was prepared by Beverly DeGraaf (Berkeley Planning Associates (BPA), January 1977).

Current definitional work within vocational rehabilitation centers on vocational goals. As DeGraaf points out, another debate in the field addressed by Congress in its deliberations prior to the passage of the 1973 law and by the literature, is whether priority to severe cases should go to those for whom the only true goal might be some degree of independent living rather than employment. The Comprehensive Needs Study (Urban Institute, 1975) advocates opening up vocational rehabilitation to non-work related services, and many studies suggest definitional schemes for classifying severity which include independent living in the disability scale. Table II at the end of this chapter, prepared by Beverly DeGraaf, summarizes the factors suggested in a number of studies and reports for use in defining severity. The definition of severity is still an issue within RSA. This table indicates the range of alternative factors considered.

Estimates of the Target Population

What is the number of individuals potentially eligible for independent living services? The policy concern is obvious. What must the program coverage be? Except for the institutionalized population, which is readily counted, the severely disabled have not been accurately estimated in any census. One difficulty, of course, is the definitional issue mentioned above. The key reference on this topic is the fourth chapter of the Urban Institute's Comprehensive Needs Study report, "Estimates of the Severely Disabled Population Not in Institutions." The Urban Institute's estimates are for the non-institutionalized, 18 to 64 years of age, and were based on the methods of the Survey of Disabled Adults (SDA) of the Social Security Administration. The following definitions were used:

- Most Severely Disabled -- Those individuals who reported that their health kept them from working at all and who actually were not in the labor force during the year prior to the survey, or who had become permanently disabled during that year.

- Severely Disabled -- Those individuals with a health condition which allowed them to work but only occasionally or irregularly. This group also includes those persons who had said that their health prevented them from working but who did not satisfy the other criteria necessary to be considered most severely disabled.

- Partially Disabled -- Those individuals who were able to work regularly but had a health condition which limited the amount or kind of work (including housework) they could do.

Using existing surveys and these definitions, the Urban Institute estimated the working age non-institutionalized population of severely disabled and most severely disabled in 1975 as follows:

Table I

Estimates of Noninstitutionalized Disabled Population, Aged 18 to 64, for July 1, 1975

	Number in thousands	Percent
Total US Population	124,800	100.0
Total Disabled Population	23,300	18.7
Most Severely Disabled	4,200	3.4
Severely Disabled	3,900	3.1
Partially Disabled	15,200	12.2

(Urban Institute, 1975, p. 72, Table 4-4)

For the institutionalized, the Urban Institute estimate was 1,786,876, or 93.3% of the total population in institutions. (Urban Institute, 1975, p. 87, Table 5-2)

These estimates from the Comprehensive Needs Study indicate the numbers of individuals who are potential clients for independent living services. The actual numbers are of course dependent upon the particular descriptions of "severity" and "need" used.

Many of the severely disabled individuals have been "invisible," living isolated lives in institutions or at home, with little integration into the mainstream of society. In recent years, some of these individuals have organized and begun to form consumer organizations and self-help groups, and to lobby for programs that would improve their abilities to live full active lives in the community. The next chapter discusses some of the alternative forms for community-based delivery of services that have emerged through the efforts of the severely disabled themselves.

Table II

FACTORS SUGGESTED FOR USE IN DEFINING SEVERITY

IN A NUMBER OF MAJOR STUDIES AND SYSTEMS

SUGGESTED ELEMENTS	RSA GUIDELINES	EXTENDED RSA GUIDELINES	NAGI	FUNCTIONAL LIMITATIONS--EMPLOYABILITY SCALE (UI)	MULTIDIMENSIONAL EVALUATION SCALE (UI)	URBAN INSTITUTE FINAL REPORT	REHAB, INC.	EASTER SEALS, IOWA	MORRALL, BERKOWITZ	BERKELEY (UI)	SMITH, LILIENFELD	McBRIDE	U.S. ARMY	RINZER	LINN	DINNERSTEIN
188 diagnoses/or specific subset	x	x					x		x	x		x	x			
Independent functioning assessment (use of transportation, social skills, communications, self-care, ADL, etc.)	x			x	x	x	x	x			x	x		x	x	x
Physical functioning assessment (bending, reaching, manual dexterity, range of motion, mobility, etc.)	x		x	x	x	x	x	x			x	x	x	x	x	
Need for multiple services	x															
Length of time in services	x															
Employment history				x		x										
Level of education				x	x	x			x							
Age				x		x		x	x	x		x	x			
Economic status, including public assistance					x				x	x		x				
Adjustment to disability					x	x										
Sex						x										
Race						x			x							
Complicating secondary conditions: obesity, substance abuse, hypertension							x	x					x			
Age of onset of disability								x								
Duration of disability								x								
Place of residence (urban/rural)								x	x							
Marital status									x	x						
Number of dependent children									x							
Multiple disabilities									x	x						
Psychiatric/personality profile													x			
Restrictions in work environment												x				

From: Berkeley Planning Associates, VR Program Evaluation Standards: A Critique of the State of the Art. Prepared for Rehabilitation Services Administration, Contract No. 105-76-4116. January 7, 1977.

IV. ALTERNATIVE DELIVERY STRATEGIES: MODELS FOR DELIVERY OF INDEPENDENT LIVING SERVICES

The phrase "independent living" has a special meaning in the disabled movement. The independent living centers that have emerged throughout the country provide, for the disabled, the linkages with services and funding upon which they depend in order to live in the community. "Independent living" means freedom from isolation or from the institution; it means the ability to choose where to live and how; it means the individual's ability to obtain the services necessary to carry out activities of daily living that non-disabled often take for granted.

Several sources provide a comprehensive overview of the range of service needs considered in independent living programs. The Comprehensive Needs Study report (Urban Institute, 1975) includes the results of surveys conducted on the service needs of individuals closed from service by vocational rehabilitation for reasons of severity, and also of individuals contacted through Comprehensive Medical Rehabilitation Centers (CMRC's). Laurie (1977) provides a review of "guidelines and experiences in independent living" which includes discussion of many of the services systems. Everett and Collignon (1975) analyze the cost and policy considerations of major service needs for improving the capacity for independent living. The BCIL Report (Fay et al., 1977) contains a checklist of relevant services (included as a section of this report).

Each severely disabled individual has unique service needs and requirements for independent living goals. No one single service prescription or housing situation will be the answer for everyone in an independent living service delivery program. Rather, the independent living movement has stressed individual choice of services and of alternatives for each service.

One problem the independent living movement has faced is the existence of gaps in existing service systems, and the lack of alternatives from which to choose. The Comprehensive Needs Study reviewed the many programs within HEW that provide services and financial assistance to the handicapped. The writers of the Comprehensive Needs Study found that the programs serving the severely handicapped are inequitable, contain severe gaps in services, suffer from inadequate control, and are operated with insufficient knowledge and resources (Urban Institute, 1975). Similar problems in children's service were found by Rand Corporation in its study on Improving Services to Handicapped Children (Brewer, 1974). The Comprehensive Needs Study report cites a major shortcoming in the design of programs for the disabled in the preoccupation with the medical aspect, "with emphasis on the dis rather than the ability, and a lack of attention to the social aspects."

In response to this disorganized and incomplete service delivery condition nationwide, there have been a variety of alternative service delivery models developed privately in non-profit corporations and with local, state and national governmental

assistance and seed monies, to explore alternatives for delivery of independent living services, and for making independent living in the community a possibility for the severely handicapped.

As we have discussed in the introduction, these organizations or centers for independent living, provide a wide range of services, which may include:

> Activities of daily living, Architectural barriers/ barrier free design, Attendant services, Chore services, Coalition development communications, Community organization, Consumer affairs information, Economic support services, Educational liaison, Employment services, Equipment repair, Home health aide, Homemaker, Housing development and adaptation, Independent living training, Information services, Legal services, Lobbying, Life support services, Medical services, Mobility skills, Outreach and recruitment, Personal care assistants (recruitment, selection, training), Public relations, Education, Recreation, Rehabilitation services, Sex education, Social services/State agency liaison, Transportation, Vocational liaison. (Fay et al., 1977).

This section discusses several of these alternative systems that have developed across the country. These programs exemplify what is happening in independent living. They provide laboratories for the demonstration of alternative approaches and visibility for the disabled in their continuing campaign for more independent living services.

Common to these programs is an emphasis on peer support and advocacy of the rights of persons with disabilities. Some of the major dimensions of difference among these programs are as follows:

Services provided in a non-residential setting versus services in a residential model. Independent living may mean living in the community, in non-segregated housing, or living in specially adapted housing projects. Sometimes these housing units have been funded through HUD. These residential alternatives do not imply institutionalization, but specialized housing. In many cases, the housing programs are integrated with service delivery.

Services provided directly versus services provided by referral to community services. In some instances, services are provided directly by the organizations, and many include transportation, peer counseling, and wheelchair repair. Most services are provided by referral to important financial services and counseling programs such as vocational rehabilitation and SSI.

Population served. The organization may serve one disability group or severity level such as the blind, the deaf, or the spinal cord disabled, or may serve many disability groups. Some organizations may maintain traditional separation by disability. The trend, however, is to organize around commonly shared service needs.

Professional base versus consumer base. In some organizational models, emphasis may be on professional service workers such as counselors, medical workers and therapists. In other organizations, there may be a consumer approach to service delivery with perhaps a "peer counselor" approach.

Vocational versus non-vocational emphasis. Independent living services were traditionally viewed in vocational rehabilitation as other than vocational. However, many independent living achievements can relate directly to vocational goals. Organizations may vary in the extent to which their overall program, and individual service components, are related to vocational goals of the severely disabled.

Transitional versus on-going services. Another basic difference in the design of these organizations is the goal of providing transitional services (say, from onset of disability until some independent living skill is achieved) or permanent sustaining services (keeping continual contact with the client, providing ongoing services in referral, counseling, and support.)

We will review several examples of independent living service models, which have achieved national prominence because of their success in helping people with severe disabilities live more independently. These examples illustrate some of the basic ways that programs in independent living vary. Perhaps the major distinction in organizing the delivery of independent living support services is whether or not the service center is residential, that is whether program participants live in the community or live in housing provided by or in the center. Therefore, the following descriptions are arranged according to non-residential and residential models.

Non-residential

Center for Independent Living (CIL), Berkeley, California

It has been stated by Laurie in Housing and Home Services for the Disabled (Laurie, 1977) that CIL in Berkeley is "the most effective self-help service program in the United States." There is no doubt that Berkeley's CIL is innovative and relatively comprehensive in its approach to independent living.

CIL serves approximately 3500 persons in the San Francisco Bay Area and represents a broad coalition of disabilities including spinal cord injury, post-polio, severe cerebral palsy, muscular dystrophy, multiple sclerosis, Fredericks ataxia, blind, deaf, multiply disabled and the elderly.

The organization's goal is total integration of people with severe disabilities into community life, or "mainstreaming." To this end, CIL provides basic services such as family counseling, personal counseling, mobility training, attendant referrals and training, wheelchair repair, self-care counseling, preventive health care, transportation, job development services, referral to important

social service agencies and programs including vocational rehabilitation, and community advocacy. These and other CIL services are designed to stabilize the environment of an individual with severe disability, thereby minimizing the handicapping aspects of disability, and helping the person gain equal opportunity.

In its advocacy work on the local, state and federal level, CIL is actively involved in the efforts to remove architectural and attitudinal barriers, and to gain equal rights for all people with disabilities. In its own community its advocacy efforts have been extraordinarily successful and Berkeley is considered the most accessible community in the country.

CIL is not a residential center. Persons who use CIL's services or work for CIL live in houses and apartments throughout the community. The organization does offer a referral service of available accessible housing and provides housing renovation assistance to improve accessibility for clients.

In addition to these services, CIL considers itself a training institution for people with disabilities; every job is a training job leading hopefully to employment in the primary labor market. Currently, CIL employs 105 persons, half of whom are severely disabled. There are training programs in computer programming and paralegal services, and a university degree program coordinated with Antioch College/West. Many people with disabilities work as volunteers within the organization. All major executive offices, and the majority of executive board seats, are held by severely disabled individuals.

Under grants and special funding from various sources, CIL has developed a number of special projects. Significant funding includes an I&E grant from the California Department of Rehabilitation, to design a strong and versatile electric wheelchair, a research and demonstration (R&D) grant from RSA, HEW, to demonstrate the effectiveness of CIL's peer counseling model for providing independent living services to the severely disabled (a part of the Comprehensive Needs Study), and a contract from the Veterans Administration (VA) to test reliability and acceptability of equipment provided by VA for the disabled.

In summary, CIL is a consumer operated service organization geared toward making support services in the community available to the disabled. Its services are both directly and indirectly provided. It utilizes community services whenever possible and aims at maximizing independence of the handicapped individuals via integration into the mainstream of the community. Other independent living programs in California have been modeled after CIL.

Residential

Most independent living models provide at least some direct residential services. As Lex Frieden points out in his paper on "Independent Living Arrangements," "residence programs may be compared on two fundamental dimensions. These are dwelling type and life support service style. Dwelling types range from single family dwellings to dormitories. Life support service styles range from informal arrangements to highly organized programs. . . Those independent living arrangements which involve large groups in multi-resident dwellings and employ many attendants in an organized program are more institutionalized than those arrangements which involve a single individual in a single family dwelling who depends on a neighbor to provide his care." (Frieden, 1975).

New Options, Houston, Texas (Cole, Holden and Frieden, 1976)

In June of 1976, the Texas Institute for Rehabilitation and Research (TIRR) in Houston began a model transitional living program, New Options, designed to foster the integration of severely physically handicapped individuals into their communities. Goals of integration may include the establishment of an independent living situation, involvement in educational and vocational opportunities, active social participation in the mainstream of society, the enhancement of important personal skills, and the medical stabilization required to maintain independent living gain. TIRR continues to support the program, which has received additional funding from RSA through an R&D grant.

Three years of experience with a previous R&D residential project, the Cooperative Living project, provided valuable background information in the design of the New Options program. Forty severely disabled young adults have lived in the Cooperative Living project since it opened in January of 1972. Cooperative Living provided a first opportunity to begin involvement in advocacy, education, vocational training, or employment. Almost all of the Cooperative Living residents made important gains in independence during their stay in the project. The program removed many constraints that existed in residents' former living environments, but contained no elements of structured transitional programming. Gains in independence thus occurred largely as a result of residents' own efforts over an average 15 month stay.

In New Options, a planned and structured program incorporates many of the features fostering independence that operated implicitly in the earlier program, but is designed carefully to provide more information and experience, and to enable participants to acquire important independent living skills in a much shorter period of time. Due to the structure, detailed studies can be made of controlled and directed transitional processes that in the Cooperative Living project were left largely to chance.

The New Options project is housed in TIRR's Maximum Independence Center, a dormitory-style building. Each project participant has a private room. The professional staff organizes group activities, and in addition, each of the staff is involved in goal-setting and problem-solving with participants on a one-to-one basis. The purpose of this counseling is to help the individual learn to solve problems on his own. In addition to the professional staff, a number of active handicapped persons from the community lead program activities.

A series of 10 training modules are in place to show participants the range of options available in:

- living arrangements
- education/vocational training and employment
- transportation
- performance of physical tasks
- meeting medical needs
- sexual relationships

and to help people develop new skills in:

- managing financial affairs
- managing attendants and budgeting energy
- developing social skills and assertiveness
- goal-setting and problem-solving

An important element of New Options, in addition to the program content, is the experience of living for six weeks in a dormitory-type setting with a non-professional attendant staff. Many participants have never been away from the personal care of family members or a nursing staff, and learning to manage attendants and direction of their own care is crucial to independent living.

Boston Center for Independent Living (BCIL) (Fay et al., 1977)

BCIL had its roots not only in the anger of disabled individuals "incarcerated" in public and private institutions, but also in the frustration of rehabilitation professionals who found the non-institutional community inaccessible to clients and patients following rehabilitation. All three co-founders had first-hand knowledge of the complexity of integrating persons with severe disabilities into the larger community. Paul J. Corcoran, M.D., now RT-7 Project Director, contributed his knowledge of medically acceptable alternative living situations and links to university support. Frederick

A. Fay, Ph.D., now RT-7 Research and Training Director and a quadriplegic psychologist, brought energy and enthusiasm from first-hand knowledge of other centers for independent living. Rehabilitation counselor Bob McHugh, with his intimate knowledge of the state vocational rehabilitation system, was a link to avenues of cooperation and funding between agencies and the idea. Their goal was a base of operations--a program rather than a facility--for disabled individuals to bridge the gap between total dependence on an institution and independent living. The BCIL founders envisioned a consumer-run self-help community integrated with the able-bodied where severely disabled persons could develop independent living skills.

In September 1974, the first resident rolled into modified quarters in Boston University's theology building and BCIL was underway. In the three years since its founding, BCIL and the roughly 50 individuals who have participated in its program have demonstrated that independent living is a realistic and preferred goal for many severely disabled persons.

Today BCIL is a small, non-profit corporation coordinating three separate phases of independence that have evolved over the years:

1. Transitional living. Providing the first basic steps in training for social and physical skills, transitional living began in modified dormitories at Boston University. As BCIL attracted disabled persons not necessarily interested in a full-time education this concept was expanded, and in March 1977, the first residents moved into a second transitional facility in Brookline Village, an apartment complex in a Boston suburb.

2. Cluster housing. For those who have mastered the skills of independent living, cluster housing offers greater independence. Located in East Boston, this is an apartment building with several apartments modified for handicapped persons, with a pool of personal care assistants and a night time attendant.

3. Independent Living. As facilities and funding for attendants became available in the greater Boston area, individuals began moving to accessible apartments, usually shared with a personal care assistant, from which they now conduct lives as students and professionals.

Atlantis

Atlantis Community, Inc., Denver, Colorado, a private non-profit program, was born out of actions taken by a group of disabled persons dissatisfied with traditional nursing home programs. This group joined forces with various organizations for the disabled--the Denver Chapter of the National Paraplegia Foundation, United Cerebral Palsy Association, Muscular Dystrophy Associaiton, Vantage House Youth Wing Council, Young Disabled Adults from Life Center, Mobility Among the Disabled, Multiple Sclerosis Society, the Denver Community Design Center, and the Mayor's Commission on the Disabled.

The Atlantis housing service originally consisted of leasing seven first floor apartments from the Denver Housing Authority. Now it offers a variety of residential living arrangements to the severely disabled. According to the project booklet, the goal of the community will be to "provide needed services while respecting the individual residents' freedom and privacy." Some of these needed services are provided directly by Atlantis, such as attendant care, transportation, housing, social activities, and counseling. Others are provided indirectly, such as medical care (via referral) and transportation by the Regional Transportation District which has adapted some buses with special apparatus.

The project is financed by a variety of means. In the past grants have been won from various federal agencies such as the Denver Housing Authority. United Way has also contributed grant money in the past to help with attendant care.

The Atlantis Community serves severely disabled persons in the Boulder/Denver areas of Colorado. Many members of this project take an active political interest in all levels of government. The program's strategy is directed towards integration into society's mainstream, maximizing traditional avenues of approach and implementing new ones when possible.

Campus Living

Campus programs have been tremendously important to the independent living movement. It wasn't until the University of California at Berkeley Cowell Hospital project, sponsored by the California Department of Rehabilitation, opened in 1962, that quadriplegic students were able to attend a university. Since that time, disabled students and others have convinced universities of the necessity of removing architectural barriers that impeded mobility on campus. Their success on campus has also affected nearby communities which slowly have become more accessible for all disabled people. The same has been true of attitudinal barriers. As disabled students became more visible on campuses and in communities and suceeded educationally and socially, they broke down many of the attitudinal barriers of the general public toward all disabled.

Many of the service delivery programs discussed earlier had their roots in a campus-based program for disabled students. CIL grew out of the Physically Disabled Students Program (PDSP) at the University of California, Berkeley, and BCIL started its first program at Boston University.

The first campus-based program began operation in the early 1950's at the University of Illinois (Laurie, 1977, p. 147). This program has grown, and continues to provide services.

UIREP and the Rehabilitation Education Center make it possible for qualified individuals with severe, permanent physical disabilities to pursue higher education and to benefit from all related experiences which are so much a part of college education and common to all students. The comprehensive approach of the program includes offering barrier-free access, both in its immediate setting and to all aspects of campus life. There are currently 150 students in wheelchairs totally integrated on the campus who live primarily in 28 large barrier-free dormitories. This program is an arm of the University, and is headed by Dr. Timothy Nugent.

Tanbrier House at the University of Illinois serves several quadriplegics or severely handicapped persons. Tanbrier House is basically a consumer-run organization with non-professional attendant care. In Tanbrier, the various duties such as hiring and firing staff, bookkeeping, and ordering of food are shared by the residents.

These programs are examples of organizational models that have been emerging in the United States in the last few years. There are many other examples that could have been cited, and other alternatives to be explored. Additional information on programs such as these can be found in Laurie (1977), which includes an extensive review of independent living arrangements and transitional projects. The BCIL Report (Fay et al., 1977), Cole and Frieden (1977), Fay (1974) and the Comprehensive Needs Study report (Urban Institute, 1975) are also relevant references.

These emerging organizational strategies for the delivery of independent living services are very significant. They represent a variety of models that have been developed in response to the obvious need for the support services that will allow the severely disabled to live in the community and free of institutional walls. In many cases, these organizations have emerged as grass-roots organizations, in store-front offices, and have survived day-to-day and week-to-week, on hope and on impermanent and sometimes fickle funding sources. That they have survived and that new organizations continue to develop based on these pioneering models or expressing new organizational forms, attests to the real need for the services and the growing pressure for independence.

V. SYSTEMATIC EVALUATION OF ALTERNATIVES: SECTION 130 AND INNOVATION AND EXPANSION APPROACHES

In addition to these community alternatives for service delivery, there are a growing number of demonstration programs, "experiments" in various strategies for offering independent living services. Notable are the six "Section 130" demonstration programs funded as a part of the Comprehensive Needs Study (Urban Institute, July 1976), and a commitment of vocational rehabilitation I&E grants monies to exploration of independent living options. Such I&E programs have been initiated by state rehabilitation agencies in California, Michigan and Massachusetts.

Section 130 Demonstration Projects

The Rehabilitation Act of 1973 authorized the Comprehensive Needs Study. This study addressed a number of the issues raised in the legislative process; however, some issues which could not be addressed were:

- Does Rehabilitation know how to serve the most severely handicapped?
- What organizational arrangements seem most efficient and effective for an ILR program?
- What other programs and services can support an independent living thrust?
- What services, especially what new services, may be required? Who should provide them?
- What manpower will be required and at what level can caseloads be handled?
- What are the approximate outcomes for given levels of expenditure? What are the costs for different types of outcomes?
- What limits should be placed on who is served (are there persons too severely handicapped to benefit even from ILR)?
- What are the objectives for an ILR Program for which reasonable accountability can be maintained?

Due to resource limitations not all of these issues could be included in the demonstration strategy. Six projects out of 22 applications were funded:

- One consumer-based model (CIL, Berkeley)
- Two models in CMRC's (University of Washington, New York State)
- Three models using the state vocational rehabilitation agency as the sole focus of responsibility for ILR (Utah, Texas Blind, Illinois)

The status and role of the projects as summarized in the Urban Institute's First Year Report (July 1976) on these projects are:

- Each project in the series illuminates more than one issue, some with greater emphasis than others.
- Each project highlights a possible service delivery model for establishment of an independent living program.
- Each project will demonstrate its ability to organize and meet objectives of an ILR-type program for persons not usually served in a state vocational rehabilitation program.
- Each project will describe experiences with other programs.
- Each project will be developing services not usually in the vocational rehabilitation program, illuminating general aspects of rehabilitation service technology.
- Each project will be developing information on cost and manpower implications.

Consumer-based model: CIL, Berkeley, California

One of the six demonstration programs selected as part of the Comprehensive Needs Study is a demonstration of the effectiveness of the peer counseling approach to service delivery used at CIL, Berkeley, California. Peer counselors, who are themselves disabled individuals, work with severely disabled clients to assist them in learning independence skills and obtaining basic survival services and resources which can then enable the client to live independently in the community. In the CIL perspective, the rehabilitation system is seen as a network of public and private agencies in which several serious gaps exist. The peer counselor serves three important functions. First and most important, the peer counselor provides a role model, that of a disabled person (two of the four counselors are in wheelchairs, one a quadriplegic) working in an organization in a profes-

sional role and living an independent lifestyle. Secondly, the peer counselor provides training in a range of independent living skills. Thirdly, the peer counselor serves as the client's link to the services that are available either through CIL, the Department of Rehabilitation, or through other resources and organizations in the community. The principal objectives of this project are to show that a consumer based organization can deliver services which may not otherwise be provided to severely disabled persons and to facilitate independent living for these individuals within the community, as well as to provide assistance in vocational exploration and job placement. Of the six projects originally funded under Section 130, this is the only project housed in a community based consumer organization.

Comprehensive Medical Rehabilitation Center (CMRC) Projects

Because the more severely disabled are more likely to have a higher proportion of medical needs, one possible approach to the delivery of independent living services is through CMRC's. Two such projects are included in the Section 130 demonstrations. (Urban Institute, July 1976).

University of Washington Department of Rehabilitation Medicine, Seattle. This demonstration is conducting comprehensive evaluations of the rehabilitation needs of person with severely handicapping conditions, and organizing state agency activities as well as community resources to provide increased services and care to the handicapped. The Urban Institute lists the specific procedures to be used in this demonstration as follows:

1. Interviewing the severely handicapped to determine their medical, housing, transportation, educational, vocational, economic and other rehabilitation needs.

2. Recommendation of appropriate rehabilitation services, based on interviews and further information gathered from evaluations of client status. For example, if medical help is indicated during the interview, medical examination by appropriate specialists would be recommended.

3. Since vocational training and counseling are frequently needed, two types of evaluation may be used: administration of interest, aptitude, and achievement tests, and on-the-job observation.

   Also, with the client's permission, observations of the work situation are performed. Assistance is provided, if needed, in job interviewing skills, resume preparation, and job seeking techniques by a vocational counselor.

4. To evaluate the helpfulness of rehabilitation services, interviews and evaluation are administered after services are provided. Services continue as long as there is need for them.

New York State Agency and the Institute for Rehabilitation Medicine (IRM). The focus of this project is the coordination of the CMRC with other rehabilitation facilities and other programs through the state rehabilitation agency itself. This tests both the coordination and case management aspects of a potential independent living program. While the Seattle project is designed as if the independent living program were assigned to medical centers alone, the New York project is designed as if a state rehabilitation agency were responsible but must work with the CMRC resource.

The basic structure of this demonstration is as follows:

> A state agency counselor is stationed with the IRM staff which includes a physician, public health nurse, social worker, physical therapist and other specialists as required. Clients will be primarily those with neuro-muscular diseases such as muscular dystrophy. Individuals go through a complete rehabilitation medicine workup, and receive medical services and equipment as appropriate, usually on an outpatient basis. Rehabilitation will be carried out with focus on the individual's home, family and work situation. Counseling in emotional adjustment to these progressive diseases, use of aids-to-daily-living, housing and transportation modification, and family counseling are included in project focus. (Urban Institute, July 1976)

State Agency Projects

An alternative way of administering independent living services is through the state agency responsible for the basic vocational rehabilitation program. That is, if the bill containing independent living provisions had not been vetoed in 1972, how might the state program be handling independent living services?

Utah State Vocational Rehabilitation Agency. The project that Utah state proposed for demonstration is aimed at provision of specialized and timely programs to include a full range of comprehensive rehabilitation services for a limited number of very severely disabled and handicapped people.

The purpose is not to serve active state vocational rehabilitation cases, but rather, to operate parallel to the vocational rehabilitation program, borrowing useful models such as the client-counselor model and innovating when necessary. During the project demonstration period, the project is developing and implementing a practical system for identifying and assessing the total needs of

the most severely handicapped.

The client population for this project includes individuals whose rehabilitation cases have been closed due to severity of disability; those individuals with catastrophic disabilities including central nervous system dysfunction, multiple orthopedic or muscular loss, muscular dystrophy, multiple sclerosis, cerebral palsy, epilepsy, severe cardiovascular conditions, severe kidney disease, severe rheumatoid arthritis, deaf, blind, and other severe neurological or orthopedic loss or disability.

The project provides services that are not routinely available to all rehabilitation clients, such as assistance in mobility, communication, social activities, and those activities necessary to maintain and restore general life functions. Vocational goals may be achieved, but clients are expected to gain in their ability to become more self-sufficient.

Texas Blind Agency. The individuals served by the Texas Blind Agency in its demonstration project are blind with one or more of the following secondary disabilities: chronically mentally ill, central nervous system dysfunction, multiple orthopedic disability, severe developmental disabilities, severe cardiac disorder, chronic pulmonary disease and/or severe auditory impairment.

This project provides a comprehensive milieu of services to test the feasibility of rehabilitation services for these individuals, who, because of multiple handicaps, are traditionally restricted from vocational rehabilitation because of severity of disability. The purpose is to determine the individual needs, develop a program to meet these needs, and to provide training in independent living.

The approach used focuses on a team approach combined with assessments of the individual client's need. Rehabilitation professionals are available to work with every client to meet his individual needs. The project utilizes three areas of expertise developed in the Texas Commission for the Blind.

- Vocational rehabilitation services to the blind multiply handicapped, as exemplified by Sunrise, which serves blind profoundly or severely retarded institutionalized young persons.

- A long established commitment to involve all available community resources.

- The team approach, which has been utilized by the Texas Blind Agency in its basic program. The project expects to demonstrate that the provision of concentrated individualized services can help clients achieve a functional level of independent living, and in some cases reentry into the traditional vocational rehabilitation process.

Illinois State Vocational Rehabilitation. The Illinois Vocational Rehabilitation agency proposed the implementation of two-way interactive cable television to individuals with the most severe handicaps who are either homebound or confined to long-term care facilities. A pilot project was planned in Peoria, Illinois to provide services and training to people in a range of living situations. Planned services included instruction to family members in physical therapy; instruction in activities-of-daily-living; and training for semi-skilled and high-skilled jobs such as insurance claims adjustment, microfilming and data entry processes. The project was discontinued due to implementation difficulties.

Innovation and Expansion Projects

Vocational rehabilitation I&E funds are being used currently to explore independent living strategies. There is potential for more development through I&E. In California, the State Department of Vocational Rehabilitation in June of 1976 made grants totaling $645,115 in I&E funds "to establish and maintain community-based and consumer managed centers for the provision of the vocational and independent living services." The I&E grants only partially fund these programs, which are also seeking support from individuals, corporations, local government and foundations in their geographic area.

In awarding these grants, the California Department of Rehabilitation was attempting to replicate the effectiveness of CIL in Berkeley, California, but recognized that the new groups would vary considerably in both organization and services delivered due to the particular characteristics of their geographic location. These centers were established in nine communities with a broad geographical spread. The groups applying for these funds also varied: three student affiliated groups; two existing non-student disabled organizations; one comprehensive rehabilitation facility; two groups of severely disabled individuals who formed for the purpose of the grant. From October, 1976 to June of 1977, 1,615 clients were served by the nine projects. The table shows the location, number of clients, services provided, and admission criteria for each project.

These projects provide direct (i.e., counseling, transportation) and indirect (i.e., community services for transportation, medical care, etc.) services. However, each of the nine projects may emphasize or not include whatever services they so desire. For example, one project emphasizes a medical supplies service, while others emphasize housing, homemaker chores and attendant services. These nine centers are, as far as line functions go, autonomous, reporting only to the Department of Rehabilitation quarterly on budgetary matters.

Currently there are plans for RSA funding of a systematic evaluation of the California I&E experience.

The states of Michigan and Massachusetts have also allocated I&E funds for development of independent living services.

Table III

CALIFORNIA STATE DEPARTMENT OF REHABILITATION
Numbers and Types of Clients Served
and Services Provided
at Independent Living Projects in California
(Innovation and Expansion)

City where project located	Number of clients served 10/1/76 - 6/30/77	Services Provided	Admission Criteria
SUMMARY, ALL PROJECTS	1,615		Need for the services offered; sometimes residence criteria in addition.
Fresno	N/R	1. Establish a center for physically handicapped; 2. Provide peer counseling and advisory services; 3. Assist in obtaining qualified attendant care; 4. Information library and newsletter; 5. Promote public awareness and sensitivity to needs of handicapped; 6. Coordinating agency services that affect disabled people; 7. Recruit and utilize volunteers to help operate the center.	Need for services
Mt. Diablo	131	1. Provide supportive services for the severely disabled and to enable them to function as heads of households, attend school, seek and retain employment, perform volunteer services, and undertake most other activities as any other able-bodied person. 2. To be an advocate for the disabled population with existing organizations and institutions. 3. Intend to offer counseling and advisory services, physical assistance, mobility services, housing information and training, and centralized information regarding other services and resources.	Individual's need for services (Physical, emotional, financial, social and educational needs will be considered).
Sacramento	80	1. Establish center for service delivery; 2. Outreach to disabled individuals previously overlooked; 3. Compilation of registers of attendants, readers, interpreters, drivers, accessible housing, sources for equipment; 4. Services for personal maintenance (attendant care, counseling, advocacy); 5. Mobility (specialized transportation, mobile repair service); 6. Newsletter, publications library.	Any individual who is unable to accomplish a given personal objective due to limitations imposed by some physical, sensory, or communications disability.
San Diego	227	1. Advocacy for clients to various community agencies; 2. Information & referral. Maintaining central resource library, laws and codes, legislative information, accessible shopping, doctors, housing. Maintain reader, interpreter, attendant lists. 3. Mobility services with purchase of a van. 4. Counseling by both peer & non-disabled for vocational, sexual, inter-personal problems, and assertiveness training.	As above
San Francisco	215	1. Along with SF Chapter of CAPH, they have undertaken jointly to establish a self-help center with ultimate goal of integration of SF residents with physical disabilities into the full life of the community.	Any person with a physical disability who feels a need for the services offered . . . Preference will be given to those persons residing in the City and County of San Francisco.

CALIFORNIA STATE DEPARTMENT OF REHABILITATION
Numbers and Types of Clients Served
and Services Provided
at Independent Living Projects in California
(Innovation and Expansion)

City where project located	Number of clients served 10/1/76 - 6/30/77	Services Provided	Admission Criteria
San Francisco (continued)		2. Services will include attendant referral and assistance, independent living skills training, peer counseling, financial counseling and assistance, housing and architectural accessibility, assistance in job placement. 3. Intend to extend and supplement the programs of Berkeley CIL in their respective areas. They will also exchange information of serving disabled and of successful advocacy with other organizations and institutions.	
Santa Rosa	203	1. Roster of attendants. 2. Advocacy for recognition of attendants (wages, skill training). 3. Wheelchair and equipment repair and service. 4. Liaison with low cost housing managers and officials. 5. Information & referral services and library. 6. Advocacy & Ombudsman service with systems & agencies affecting handicapped people. 7. Communications network between handicapped people within the county.	Dependent upon need.
Van Nuys	72	1. Outreach for severely disabled. 2. Financial counseling. 3. Recruitment & screening of attendants/homemakers; maintaining lists for referral. 4. Inspect apartments & housing for suitability of use by disabled clients. Inspect & offer consultation on new construction. 5. Refer disabled clients to appropriate agencies for services. 6. Publish monthly newsletter. 7. Provide 24 hour answering service. 8. Maintain speaker's bureau to speak on problems of handicapped before public agencies, private groups, in hospitals. 9. Provide counseling service.	Anyone asking for services in person, in writing or on on the telephone
Watts	564	1. Peer counseling, individual family and group counseling. Drop-in rap sessions. 2. Pre-vocational counseling. 3. Financial aid counseling. 4. Referral services for attendants/homemakers, readers for the blind, interpreters for the deaf, service people to do minor modifications; referral to proper agencies, listing of accessible housing. 5. Reference library will catalog journals, books & articles relevant to the needs of the disabled. 6. Equipment Loan Bank. Donated "sickroom" equipment will be stored and available for loan. 7. Attendant recruitment service and management course. Attendants will be recruited and screened. 8. Self-help health program. A lecture series on preventive medicine for the disabled. 9. Low-vision aides will be provided for partially-sighted.	Any physically disabled adult may apply.

CALIFORNIA STATE DEPARTMENT OF REHABILITATION
Numbers and Types of Clients Served
and Services Provided
at Independent Living Projects in California

City where project located	Number of clients served 10/1/76 - 6/30/77	Services Provided	Admission Criteria
Watts (continued)		10. TTY terminal will be provided and limited interpreter time for the deaf. 11. A wheelchair-accessible van will be bought for transportation. 12. Surveys conducted for lists of accessible housing.	
Los Angeles	123	1. Outreach to identify, serve & refer disabled clients to appropriate agencies. 2. Provide crisis intervention services by hot-line counseling and/or in-home counseling. 3. Provide counseling services to overcome problems of disabled in socialization, family relations, sexual adjustment & spiritual adjustment. 4. Provide activities of daily independent living skills to families of disabled. 5. Provide advocacy & referral services. 6. Provide special interest workshops to the disabled. 7. Develop a goal attainment scaling model appropriate for use with the minority disabled.	A person must be disabled and live in, or be a student at a school, college, or university located within the target area.

While these programs do represent increasing governmental commitment to exploring the potential of independent living service delivery, there remain basic questions about the costs of such services if provided throughout the nation. The Section 130 projects, now well into their third year, routinely collect cost information and should provide meaningful program planning data. In addition to evaluation of program impact and demonstration of a program's ability to serve severely disabled clients and to fill gaps existing currently in rehabilitation services, the Section 130 projects and the many other independent living programs in the country can provide needed information on the costs of coordinating or directly delivering independent living services.

In the next chapter, we will review some of the studies that have been done on the costs of independent living programs and the economic issues of independent living.

VI. COSTS AND BENEFITS OF INDEPENDENT LIVING

Traditional economic justification of vocational rehabilitation services for the disabled has rested on the program's focus on gainful employment. As we have seen, the vocational mandate in rehabilitation services has persisted despite legislative attempts since 1959 to extend rehabilitation benefits to persons for whom no vocational objective is obvious. This vocational emphasis brings with it an eligibility requirement that clients be "feasible," that is, that they be potentially employable. Those individuals disabled to the degree that their participation in the labor force is considered "infeasible" are refused services.

With the change in mandate in 1973 to serve, as a priority, the severely disabled, there has been some experience in the system with economic costs associated with such services. But because of the formative nature of independent living concepts and programs, the economics of independent living is still an emerging field. Traditional economic analysis of vocational rehabilitation stresses gainful employment, reflecting vocational rehabilitation's legislative mandate. Even if the legislative mandate is expanded to permit independent living closures, difficulties in defining independent living gain and its dollar values present a major obstacle in economic analysis. Such analysis is critical. As Berkowitz et al. point out (White House Conference, Awareness Papers, 1977):

> Clearly chances of handicapped individuals achieving their goals are enhanced if they can establish that expenditures made on their behalf are justified and thus provide the basis for continued and expanded efforts on their behalf.

Most benefit-cost ratios computed for the basic program in vocational rehabilitation show a substantial return to society for investment in services. Conservative estimates indicate a benefit-cost ratio of 5 to 1. Berkowitz (White House Conference, Awareness Papers, p. 234) agrees with the conservative figure, but cites ratios as high as 70:1. These benefits are based on earnings of rehabilitated clients. In considering a program of independent living, outcomes other than gainful employment may be included. A conclusive benefit-cost analysis has not been done. But policy-makers and analysts have expressed some concern about the costs of such programs. In vetoing the 1972 Rehabilitation Act, President Nixon charged that the bill "would seriously jeopardize the goals of the vocational rehabilitation program and is another example of fiscal irresponsibility" (Urban Institute, 1975).

Costs

Cost is a major policy issue. The Comprehensive Needs Study developed cost estimates by considering a program to serve only the

18-64 age group of 68,000 individuals closed for severity by vocational rehabilitation in 1972. With modest assumptions of care needs -- two round trips per week by taxi, one hour a day for an attendant, one hour per week for a home health aid, one meal per day brought to the home, four hours of counseling per year, and, for 10% of the individuals $1,000 in college tuition--the total estimated cost per year was $115,100,000 (Turem, 1976).

Table IV

Annual Cost Estimates of Modest Program to Serve the Handicapped Rejected by VR

Service	Unit Cost	Units	Persons	Costs ($ millions)
Homemaker/attendant	$ 3.00 per hour	365	37,400[1]	41.0
Home health	$11.00 per hour	52	27,900[2]	16.0
Meals on Wheels	$ 1.55 per meal	365	37,400[1]	21.2
Transportation/taxi	$ 6.00 per round trip	104	37,400[1]	23.3
Counseling	$25.00 per hour	4	68,000	6.8
Education	$1,000.00		6,800	6.8
TOTAL				115.1

1. 55 percent of our sample were dependent, a proportion used here.
2. 41 percent were moderately to totally dependent.

(Turem, 1976, p. 646)

An internal RSA memo on "Independent Living," dated July 1977, cites this cost estimate in discussing current policy and costs of programs. It is important to realize how conservative the figure of $115.1 million really is, in considering provision of independent living services to the population in need. The Urban Institute emphasized that these costs are associated with modest assumptions of care needs of only 68,000 individuals. In fact, the costs indicated are those associated with maintaining an independent lifestyle with a relatively low level of services (for instance, the estimate assumed one hour of attendant care per day--many individuals with severe disability require attendant care for five or more hours per day). These are unit costs for a low level of service use, not total estimates for a program that provided CIL-type services across the country.

To give some idea of the difference in scale between the Urban Institute estimate, and the likely real social costs of such services, some benchmark statistics from the state of California Homemaker/Chore services will be helpful. The Homemaker/Chore program, as has been mentioned, pays for attendant care, and has provided, in California, the attendant system that makes independent living possible for many in the state. In 1976-1977, this program spent $115 million dollars, serving 72,000. 65% of the population served were elderly, 30% disabled, and 5% blind. Approximately 9% of all served were severely disabled, needing 20 hours/week Homemaker/Chore services. In 1977-78, projected expenditures are $140 million. Estimates from Homemaker/Chore services indicate that the severely disabled individuals served in 1976-77 used 32% of the funds, or $36 million dollars.* These figures should indicate how conservative the Comprehensive Needs Study estimates really were. The figures indicate not the level of resources needed for independent living, but merely for some support services.

Some of the more specific reports prepared as a part of the Comprehensive Needs Study do provide more detail of the sort needed for a more comprehensive cost estimate. For example, Everett and Collignon (1975) conducted an extensive study on Cost and Policy Considerations in Improving the Capacity for Independent Living of the Most Severely Handicapped. In this study the authors have presented estimates of independent living needs and the costs and benefits of implementing the following programs for independent living needs of individuals most severely handicapped: transportation, relocation, architectural barriers and housing, medical care, employment, and other consumption activities. As a part of the Comprehensive Needs Study, this study analyzes the costs and some of the impacts of the various alternative services mentioned above, and the approaches for meeting the needs of the most severely handicapped.

In a related study, Cost Analysis of Alternative Transportation Systems for the Handicapped, by Jones (1975), various ways of improving the mobility of the 7,600,000 persons in the US who suffer from chronic mobility limitations are looked at primarily with consideration of the impact and cost of each alternative. The alternatives discussed are: curb modification, wheelchairs, modified automobiles and vans, fixed route transit system, demand-responsive systems, and mobility counseling. With specific regard for independent living this paper states that "the non-economic social benefits accruing to over 3 million unemployable handicapped persons provide compelling reasons for implementation of a national program" (p. 62). The paper concludes that a national mobility-improvement program should include curb modification, door-to-door transportation service, the phasing-in of the "transbus," limited subsidies for modified automobiles and vans, and the provision of power wheelchairs and mobility counseling to those persons needing them. The analysis indicates that such a program would return substantial social and economic benefits, including a $6.4 billion increase in the earnings of the handicapped.

* Mike Perine, California Department of Health, Sacramento, CA.

The paper also concludes that adapting existing subways and buses, and building accessibility into new subway systems, are not cost-effective solutions to the mobility problems of the handicapped.

Looking at costs from another point of view, Frieden, in a paper titled "Independent Living Arrangements for the Severely Disabled Person" (1975) speaks of housing for the disabled not as solely housing, but an entire "life support system." According to Frieden, the suitability of the housing determines the independency or dependency of its occupants. The author presents a philosophic and pragmatic approach to independent living which includes an everyday cost breakdown of living expenses such as attendance fees and scheduling, food expenses, and transportation costs. The author compares the costs and benefits in quasi-economic terms for multiresidence (i.e., occupied by more than one individual) versus living alone. As might be expected, costs are higher in single unit dwellings as compared to multiresidences. Benefits in this study are basically seen as intangibles: freedom, privacy, social interaction, self management; whereas costs are measured in dollars.

Benefits

Frieden's paper points out a central problem in the economic analysis of independent living programs; that is, the measurement of "intangible" or no-dollar benefits associated with a disabled person's gain--in self-esteem, in choice.

Estimation of an Individual's Non-income Gains

The Valuation of Homemaker Services (Loshin and Collignon, 1975) illustrates that services not traditionally included in the economic arena can indeed be given a dollar value. Estimation attempts in this study have included opportunity cost estimation of women who are homemakers, and, alternatively, the replacement cost estimation of homemakers. The findings of this study offer recommendations for methods of calculating accurate replacement cost estimates.

Another relevant study, contracted by RSA, is being conducted as a part of the development and refinement of vocational rehabilitation program evaluation standards (BPA, 1977). This work includes consideration of standards for measuring non-vocational or independent living outcomes. The work builds on a previous study of non-vocational outcome measurement conducted for the California Department of Rehabilitation (Schmidt, 1976).

Attempts to measure benefits of other-than-gainful employment represent an important step in the economic analysis of independent living. It is important to consider that from a social cost point of view independent living programs may create a net social gain due to:

Reduction of costs of institutionalization. Many argue that, in fact, it costs more to maintain an individual in an institution than to provide the services and dollars that the same person needs to live independently (Laurie, 1977).

Support for gainful employment. Many severely disabled individuals, when given adequate equipment and services, are a part of the active work force. Countless others want such an opportunity. The benefits and costs of the gainfully employed severely disabled should be reviewed more carefully. Studies conducted with Washington and Michigan State Vocational Rehabilitation data showed that severely disabled individuals are not more difficult to rehabilitate for employment than other vocational rehabilitation clients, although closure is more costly (Collignon, Dodson, and Skaburskis, 1975).

There is much work that remains to be done on the economics of independent living. Economic justification of investment in independent living programs is an important policy concern. But we should be equally aware of the importance to the disabled person of the choices and the independence that the non-disabled take for granted. Some of the intangibles associated with self-esteem and independent living gain will never be a part of a benefit-cost calculation, but they are centrally important in the lives of the individuals with severe disability.

VII. CONCLUSION

In Chapters I to VI, we have reviewed major policy issues and programmatic developments in independent living for individuals with severe physical disabilities. The new concept of independent living combines ideas from three related concepts: independent living as physical modification and aids to daily living; independent living rehabilitation; and independent living as a consumer rights movement.

The concept is that of a complementary network of services, available from the onset of disability throughout the individual's life. This concept is exemplified in many independent living service organizations around the country. The concept has six important elements:

- Focus on the individual with disability and maximization of that individual's opportunity for participation in society.
- Provision of the services needed by that individual, either through established service organizations such as vocational rehabilitation and HUD, or through independent living centers that integrate a variety of public and private services available in the community, and provide other services not available elsewhere.
- Focus on choice for the individual, on alternative ways that housing and service needs might be met.
- Integration of an individual's need for support services and achievement of "habilitation" or a living situation that works, with life goals such as vocational and educational objectives.
- Provision of both "crisis" or intervention services, related to the onset of disability, and on-going services that support stabilization and individual development during and after "rehabilitation."
- Advocacy of the rights of individuals with disability.

In meeting these objectives, program developers have used a number of alternative organizational approaches. Major dimensions of these current programs include:

- Services provided in a non-residential setting versus services in a residential model.

- Services provided directly versus services provided by referral to community services.

- Population served: one disability group versus integrated group.

- Professional base versus consumer base.

- Vocational versus non-vocational service plan objectives.

- Transitional versus on-going services.

Several examples of independent living service models were reviewed: CIL, Berkeley; New Options, Houston; BCIL; Atlantis, Colorado; and campus living programs.

Policy-makers are looking to these centers and service programs as possible models for expansion of services to the severely disabled. Some formal evaluations of alternatives for service delivery have already begun. In addition to evaluation components in some of the above models, there are evaluation studies being carried on in Section 130 demonstration projects funded as a part of the Comprehensive Needs Study:

- one consumer-based model (CIL, Berkeley)

- two models in CMRC's

- three models using the state vocational rehabilitation agency as the sole focus of responsibility for ILR: Utah, Texas Blind, Illinois (Illinois now discontinued)

Further systematic investigation of independent living alternatives is planned by the California Department of Rehabilitation through their I&E program.

The Rehabilitation Act of 1973 provided the basis, within vocational rehabilitation, to investigate extension of independent living services to the severely disabled. A number of notable events provide landmarks in the rapid change in independent living from an idea to a more and more clearly defined expression of need for services, legislation, and resources. These landmarks in the articulation and development of independent living include:

- The Comprehensive Needs Study and its five ongoing demonstration projects, based in hospitals, state vocational rehabilitation programs, and in a consumer-run organization.

- The first national Conference on Independent Living, sponsored by RSA and held at the Claremont Hotel in Berkeley, California in October 1975. The newly emerging concept of independent living clashed with more traditional, maintenance-based concepts in this conference.

- The inclusion of independent living topics in important national rehabilitation planning conferences. For instance, at the 1977 National Conference of the Council of State Administrators of Vocational Rehabilitation (CSAVR), an entire afternoon agenda was devoted to discussion of independent living and where, governmentally, an independent living program might be housed.

- The increasing interest in exploring independent living alternatives, as in the recent allocation of state I&E dollars to the development of independent living programs, and the evaluation of the program's ability to deliver needed services and to integrate independent living services with the vocational rehabilitation basic program.

- Development of new professions, such as peer counseling, where disabled individuals counsel other disabled individuals on activities of daily living, disability experience, and provide role models for independent living.

- The inclusion, in the White House Conference on the Handicapped, of papers on housing and service needs for independent living, and the economics of disability.

- The recent opening, within HUD, of an Office of Independent Living.

- The recent, successful mobilization of disabled people nationally, in San Francisco, California, and then Washington, D.C. to force the long-delayed implementation of the Section 504 of the Rehabilitation Act of 1973.

- RSA funding of a second national Independent Living Conference, to be held in 1978 in Texas.

While these are all indicators of rapid advances in independent living, there is still much to be done. More alternatives should be explored. The existing centers for independent living have begun to develop intervention strategies and support systems. There are many arrangements and programs that should be tried. Among them are:

- Research on the appropriate outcome measures of independent living rehabilitation.

- Exploration of the relationship of aspects of independent living programs such as peer counseling, to the vocational rehabilitation basic program.

- Investigation of new strategies for intervention.

- Data and analysis of the costs of providing independent living services.

- Longitudinal information on the benefits of independent living services.

- Clarification of the major definitional issues impeding implementation of independent living legislation.

- More investigation as to the organization structures most effective and efficient in the provision of independent living services, through an expanded program of experiments and demonstration projects.

In testimony before the Senate Subcommittee on the Handicapped, Jerry S. Turem, Project Director for the Comprehensive Needs Study, stated:

> If the Congress is desirous of an independent living program we would think authorization levels far in excess of those included in the previous bills would be called for, if only to cover those persons presently closed for severity. We would think that an authorization of 30 to 80 million dollars would be most usefully spent on a project grant program modeled after the Innovation and Expansion Grant Authority which would establish a series of projects to investigate various approaches, assess the most effective and efficient means for providing such services, and work out the optimal interrelationships with other delivery systems. (Turem, 1976, p. 660)

Corgress, in funding the Comprehensive Needs Study, had been concerned with a number of policy questions that remain today:

- Does Rehabilitation know how to serve the most severely handicapped?

- What organizational arrangements seem most efficient and effective for an ILR program?

- What other programs and services can support an independent living thrust?

- What services, especially what new services, may be required? Who should provide them?

- What manpower will be required and at what level can caseloads be handled?

- What are the approximate outcomes for given levels of expenditure?

- What are the costs for different types of outcomes?

- What limits should be placed on who is served (are there persons too severely handicapped to benefit even from ILR)?

- What are the objectives for an ILR program for which reasonable accountability can be maintained?

While many of these questions remain unanswered, the evidence seems to indicate that centers for independent living, following the definition described in these pages, provide the most viable and dynamic answer to consumer choice and participation.

As the BCIL Report (Fay et al., 1977) states:

> The Comprehensive Needs Study of Individuals with Most Severe Handicaps (Urban Institute, 1975) presents "the setting up of consumer self-help organizations to fill vital gaps in the disability service delivery system" as a major policy option for implementing rehabilitation for independent living . . .
>
> While not all such programs need to organize and operate as CIL (Berkeley) is, public policy-makers should investigate the potential of such a model for filling this needed function in the rehabilitation system.

REPORTS FROM THE FIELD

Much of the information in this review has come from printed materials and reports. The independent living movement is such a dynamic process that several national leaders in the movement have been invited to share in this paper their own reports of progress in their areas of the country. Ed Roberts, Fred Fay, Lex Frieden, Don Galloway, and Judy Heumann represent a broad range of organizational perspectives. Ed Roberts is Director of California's Department of Vocational Rehabilitation. Fred Fay is Research Director of Research and Training at Tufts' Rehabilitation Research and Training Center. Lex Freiden is New Options Research Director with Texas Institute for Rehabilitation and Research. Don Galloway is Executive Director of the Governor's Office of the Handicapped in Colorado. Judy Heumann is Deputy Director of Berkeley's Center for Independent Living. All of these authors share first-hand experience in independent living. Because of their diverse current positions, their reports provide information on a number of facets of the current independent living movement.

California

By Edward V. Roberts
Director, California Department of Rehabilitation

The Sixties marked the beginning of the disabled rights era in California and the birth of the independent living movement in Berkeley. The political activism of disabled and elderly individuals, parents of disabled children and consumer organizations such as the National Federation of the Blind (NFB) and the California Association for the Physically Handicapped (CAPH) created pressure for change.

California's Homemaker/Chore legislation was a major victory for disabled and elderly activists and insured that an individual with a severely disabling condition would have sufficient funds to hire an attendant to help care for survival needs. As a result, California became the one place in the country where a severely disabled person who was reliant on SSI could hope to live independently.

The independent living movement began at the University of California in Berkeley. In 1962 I was the first severely disabled student at UC. Since I spent most of my time in an iron lung, it was decided that the only feasible arrangement would be a room at the Student Health Service-Cowell Hospital on Campus. Within the next three years there were 12 severely disabled students in the Cowell Resident Program, which by then had been formally established and was being supported by the California Department of Rehabilitation.

At Cowell, we learned a lot from one another. We began to understand the degree to which we had relinquished control of our lives to medical and rehabilitation professionals, and to realize that the concern about self determination raised by the black and student movements had considerable relevance to our own lives as disabled people. It was out of this new political consciousness of the Cowell residents that the PDSP* was born in 1970 and CIL in 1972.

From the beginning PDSP and CIL made a firm commitment to three basic principles as recorded by Hale Zukas of CIL:

1. Those who know best the needs of disabled people and how to meet those needs are the disabled themselves.

2. The needs of the disabled can be met most effectively by comprehensive programs which provide a variety of services.

3. Disabled people should be integrated as fully as possible into their community.

* See page 25.

In addition CIL was set up as an organization serving and representing a wide range of disabilities. In its commitment to a coalition of disabilities, CIL laid the groundwork in California for the broad-based disabled movement that was to come into prominence over the signing of regulations of Section 504 of the Vocational Rehabilitation Act in 1977.

During the Seventies, CIL emerged as the national model of a comprehensive community based service system, run by disabled people and providing a wide range of programs that promoted independence. It did not come easy. The organization struggled endlessly with funding problems. But a number of local foundations, individuals, and the University of California at Berkeley helped it over the rough spots as it slowly developed a relatively firm base of community and government support.

In 1973, RSA, Region IX office, recognized a diamond in the rough in CIL. We had some answers, not all of them--but the ones we had were really working and needed to be brought forth. RSA understood that what was happening in Berkeley could be very important to the entire rehabilitation system and over the next few years helped to polish that diamond. Gradually, a feeling of partnership and common concern developed between CIL, RSA and the California Department of Rehabilitation. It was a cautious relationship as each learned to trust the other, but it led to important advances for the independent living movement. In 1974, Region IX helped CIL begin a program to train rehabilitation counselors who, as a result of the Rehabilitation Act of 1973, were suddenly expected to serve severely disabled clients. In 1975, RSA contracted with CIL to demonstrate the effectiveness of its peer counseling approach to the vocational rehabilitation of persons with severe disabilities (CIL R&D Project, Urban Institute, 1975, p. 821).

During this time CIL, in cooperation with other disabled and elderly consumer organizations, was deeply involved in a major advocacy effort to open the way for greater integration into the community and equal opportunity for the severely disabled in education, transportation, housing, employment and social services.

It was the potential importance of the Independent Living movement to vocational rehabilitation that led Governor Jerry Brown to appoint me as Director of the California Department of Rehabilitation in November of 1975. It was understood that I would use my experience as Executive Director of CIL to bring greater consumer involvement into the state vocational rehabilitation system and to expand the opportunities within the system for people with severe disabilities to integrate socially and economically into society.

The past two and a half years have seen many changes in California in terms of new opportunities for people with severe disabilities to achieve greater social and economic independence. Our urban environments have become more accessible as the Department of

Rehabilitation, CAPH and other groups have pressed for full compliance with architectural barrier laws. Accessible public transit has become a statewide policy and in Los Angeles, San Diego, San Jose, and other communities, public transit systems have made a strong commitment to making their buses accessible.

Affirmative action programs in both private business and state agencies are being revamped to insure that disabled people gain better job opportunities. In the last year alone, the Department of Rehabilitation assisted 30 major corporations in the development of new affirmative action plans to hire disabled--and that's before Section 504 of the Rehabilitation Act was implemented.

Fourteen new independent living programs, modelled after the CIL in Berkeley, have sprung up throughout the state. Nine of these programs were stimulated by Departmental I&E grants, and all of them have joined with CIL in a coalition that is already influencing the state's social service system.

We are looking to the independent living movement for models that will serve other disabilities. We are showing through the Mentally Retarded Private Institutions (MRPI) program, funded by the California Departments of Health and Rehabilitation, how persons who are mentally retarded can be helped toward greater independence through small, transitional living/training facilities that stress socialization and independent living skills, and how task analysis techniques can transform the training process.

Through the new advisory committee structure in the Department of Rehabilitation and throughout state government, consumers and consumer groups are gaining increased input into programs. The main advisory body to the Department of Rehabilitation has been completely reorganized and now represents the major statewide consumer/provider organizations in California. Its $40,000 budget and authority to review all major policy changes within the Department insure consumers of a far greater impact on the California rehabilitation system than ever before.

Of major importance to the human rights movement of the disabled in California is the current effort of disabled organizations and the Department of Rehabilitation to bring about changes in the laws and regulations governing welfare benefits. As federal SSI and SSDI laws now stand, a person with a severe disability who earns $200 a month or more loses all welfare and health benefits. This is regardless of the fact that his earnings are insufficient to cover daily living and health care expenses. This fear of losing essential life-support services forces many people with severe disabilities to choose welfare over employment. Bill AB 922, which provides state money for the continuation of Medical and Homemaker/Chore benefits on a sliding scale relative to income, is now being considered by the California legislature.

Passage of the bill would provide a major incentive to people with severe disabilities as they work toward greater independence and self-sufficiency. Such legislation is desperately needed in other states and on the federal level.

Centers for Independent Living in New England

By Frederick Fay, Ph.D.
Director of Research and Training
Tufts Rehabilitation Research and Training Center (RT-7)

In most communities, the quadriplegic individual who needs assistance with dressing, transfers, or feeding can have major problems if he or she doesn't have family or friends to help with attendant care. Far too many "severely physically disabled" persons have ended up in nursing homes, hospitals, or state institutions where the "level of care" is both physically and mentally dehumanizing. Centers for independent living can enable quadriplegics to bridge the gap between such negative environments and independent living in the community.

Cooperative efforts by rehabilitation professionals and disabled consumers have demonstrated that community-based independent living is a medically acceptable, cost-effective, and personally rewarding alternative to long-term institutional care for severely disabled individuals. Indeed, in the years since passage of the Rehabilitation Act of 1973, independent living has rapidly become one of the by-words of rehabilitation.

Following the initiative of centers for independent living in Champaign, Illinois, Berkeley, California, and Houston, Texas, the project to establish BCIL was conceived in January 1974, and opened its doors in September of that year. To date, 50 individuals have been through the program. Within three years, using BCIL as precedent, other centers for independent living were established in Worcester and Amherst, Massachusetts, and Bangor, Maine. As this report goes to press, centers for independent living are on the drawing board in Vermont, New Hampshire, Rhode Island, Connecticut, and southeastern Massachusetts, with BCIL and RT-7 input.

Most of the New England centers for independent living have focused primarily on persons with severe physical disabilities--such as spinal cord injury, or cerebral palsy--and most include a transitional housing program.

The groundswell of interest in independent living is the result of determined efforts by disabled individuals who have demonstrated a truly pioneering spirit in breaking away from institutions --sometimes in defiance of health professionals--and in learning how to care for themselves in the job market. These individuals have had the assistance of rehabilitation professionals who were distressed by the limited futures of those for whom the promise of America was visible only on a flickering TV screen in a back bedroom or hospital ward.

Two lessons stand out as important from the BCIL experience. First, BCIL has shown that it is possible to develop a quality independent living rehabilitation program in a short period of time. Second, it is important to think through every step of the center for independent living's development. No two centers are alike. Differing funding sources, philosophies, organizational structures, goals and residents influence the particular character of any organization. However, at least two philosophic tenets appear to provide common links between BCIL and other centers:

1. People with disabilities plan and implement the decisions that affect their lives.

2. The programs are aimed at enabling persons with disabilities to live independently in the community rather than be dependent on institutional living.

The growing number of centers for independent living in New England, combined with those in other states, are part of a broad national consumer movement. In this movement financial considerations are vital.

The county and state hospitals where many disabled individuals were living before coming to BCIL were costing well over $100 per day. Medicaid now only pays a small portion of that for the same individual to BCIL. The climbing costs of health care could be a final blow or a growth incentive to the center for independent living movement. Medical progress will continue to produce more and more severely physically disabled individuals who will require personal care assistance on a daily basis. These persons will continue to gravitate to hospitals and nursing homes as long as cheaper alternatives are not available to the state.

The key words are "cheaper" and "available." Centers for independent living must remain available in every community. Cost controls must be built in to insure that they continue to represent a less costly alternative than nursing homes and chronic care institutions. If it is cheaper to warehouse disabled individuals in such institutions, then only eternal vigilance by the handicapped consumer organizations will prevent this from happening. If, on the other hand, centers for independent living can offer a cheaper alternative to the system, then the institutional system and state governments will welcome and support the alternative.

Legislation and regulations can be altered to make it easier for centers of independent living to be developed. Difficulty with recent legislation and regulations include:

- An inappropriately large emphasis on medical input and supervision; and

- An orientation toward institutional providers for service, whether program management or personal care services.

Regulations are needed which will encourage the provision of funds directly to the disabled individual for use in hiring and reimbursing his or her own personal care provider. This would reduce agency overhead and increase accountability of the care provider directly to the disabled person.

Legislation to provide "front money" for starting new centers for independent living is necessary. The most dramatic outcome of the move toward independence was the announcement in May, 1977, by HUD Secretary Patricia R. Harris that HUD would sponsor an Office for Independent Living. With this type of support from the federal government for housing, and expanding HEW support for services, possibilities for future growth and development of centers for independent living are greatly enhanced.

HEW's RSA gave centers for independent living a boost in their manual, Chapter 25 on "Policy Development Consultation." (USDHEW, RSA, 1975) Generally, the chapter lays out optional methods for consumer involvement in the planning, delivery, and evaluation of rehabilitation services. Specifically it presents the following as one of the areas where consumer representatives should work closely with the state vocational rehabilitation agency's director and his or her representatives:

> Assistance in the establishment of specialized facilities and programs to be operated by consumer and other groups through funding by the State agency, to meet the special needs of the severely disabled applicant or client such as peer counseling, centers for independent living, halfway houses, and other transitional living arrangements, transportation and post-employment services.

Consumer involvement in rehabilitation services, long a buzz word phrase, is becoming a reality. In a recent CSAVR survey on independent living, a significant number of vocational rehabilitation directors indicated their preference that "consumer managed self-help organizations," such as centers for independent living, be designated as the entity responsible for the provision of direct independent living rehabilitation services.

The climate appears ripe for a major new federal legislative thrust for establishing a rehabilitation for independent living program. In the past four years, the percentage of vocational rehabilitation directors supporting rehabilitation for independent living programs has climbed over 60% (mail survey by NRA of vocational rehabilitation directors in 1973) to 75% (Urban Institute, 1975), to 92% (CSAVR, 1977). President Carter, in his position paper, "Jimmy Carter on Americans with Disabilities," stated "We must broaden the traditional concepts of rehabilitation to include independent living as a supported rehabilitation objective."

Perspective on Houston: The Budding of a Seed

By Lex Frieden
New Options Research Director,
Texas Institute for Rehabilitation and Research

In 1971, the Cooperative Living Residential Program started in Houston. Sponsored by RSA and Rehabilitation Research and Training Center 4 of HEW, this project provided the first taste of independent living for more than forty severely physically disabled individuals. Five years later in 1976, more than 200 severely physically disabled individuals who before that time had been institutionalized in nursing homes or their parents' homes, were living independently in four different residential clusters and in private homes and apartments scattered throughout the city.

Today, this growing movement towards independence is about to take a quantum leap; small groups of persons with a variety of types of severe disabilities are graduating from the New Options transitional living program every six weeks armed with the skills they need to live independently. Independent Lifestyles, an incorporated group of severely physically disabled persons who share attendant services, recently moved into Banyon Condominiums, which they planned, financed, and developed themselves. The Texas State Department of Public Welfare is about to initiate a major demonstration project designed to facilitate independent living for severely disabled individuals who before this time had been restricted to nursing homes. The Houston Housing Authority has committed more than a million dollars to purchase and remodel facilities to be used for independent living by handicapped individuals. The Texas Rehabilitation Commission is in the process of implementing a statewide, state legislated, and state funded extended rehabilitation program to provide independent living and vocational opportunities for hundreds of severely disabled persons who were heretofore not eligible for vocational rehabilitation services. Together these programs should provide a wealth of opportunities for severely disabled individuals who want to live independently in the community.

There is no doubt that independent living is of age. Federal legislation will soon recognize it and society will benefit from it. However, we must all be cognizant of the fact that independent living is a manifestation of learned skills and behavior. Therefore, we must concentrate in order to learn, and we must practice in order to remember. Furthermore, we must realize that some of us may have difficulty in unlearning old behaviors and others may have neither the motivation nor the aptitude required to learn to live independently.

Another point which should be made about independent living by severely disabled individuals is that some kind of supportive environment is required. Some of the implications which follow are paramount. For example, the design of supportive environments may be complicated and tedious. Supportive environments must be carefully maintained and constantly updated. Finally, supportive environments and programs are subject to exploitation and control by individuals who do not necessarily depend upon them. For all these reasons, severely handicapped individuals who must depend on a supportive environment in order to be independent should assert themselves in the planning, management, and administration of independent living programs.

The final point to be made here is that independent living cannot be a reality overnight. Just as the handicapped individual who has adapted to a dependent lifestyle must learn new skills in order to be independent, so must supportive resources and programs be developed and reshaped in order to meet the needs of disabled people who choose to live independently as opposed to those who do not.

While independent living is indeed a reality for many severely disabled individuals throughout the United States today, it is still only a dream for countless others. Some persons have succeeded at capturing the essence of independent living in spite of over-protective restrictions and program disincentives. Others have chosen to forego the promise of freedom offered by independent living in order to avoid the responsibility of making decisions or the insecurities of self reliance.

In conclusion, experience has shown that independent living may not be an alternative for everyone. However, given an adequately supportive environment and certain adaptive skills, most severely disabled individuals who wish to live independently will certainly be able to do so.

Independent Living for the Disabled in Colorado

By Don Galloway
Executive Director, Governor's Council on the Handicapped,
Colorado

Developing independent living skills has been both a challenge and a series of good luck situations in my life. As a blind person I am able to live independently and am assured that all disabled persons should have that same opportunity.

I lost my sight at the age of sixteen. My family played a really important role in my growth and development. Instead of treating me like a dependent isolate who was incapable of adequate functioning they treated me as just another member of the family who happened to be without sight.

This attitude was the most important gift they could have ever given me. It helped to structure and shape my attitude about myself and my disability. I have always felt that I am able to do anything I put my mind to. In California, where my family migrated, many opportunities were opened to me. These included good educational training, travel and many interesting social contacts.

I have graduated from several colleges, married, had children and worked in progressively expansive employment settings. Having self-confidence and esteem have contributed to making it possible to structure my environment to obtain the most possible benefits for personal growth and expression.

To me, independent living means understanding the various components of society (e.g., housing, transportation, employment, recreation), that affect one's life so that he can use them to meet his own needs.

Each state, county, and city has a different set of supportive systems to serve these functions. In Colorado here is a bit of what you can expect in the areas of:

- Financial considerations
- Living situations
- Transportation
- Legal aspects

Financial Considerations

The majority of severely disabled people derive their income primarily from either federal, state or local government assistance

programs. These programs can be divided into four categories.

A. Income for living expenses: money in the form of cash grants for basic daily living expenses such as rent and food.

Colorado has a "maximum level of income" which they consider necessary for survival in a minimal way. This is set at $185.00 per month. Sources for these funds are:

1. US Government contributions of $167.80 in the form of SSI. An SSI recipient can earn up to $65.00 per month without losing his SSI. However an earned income above $65.00 has $1.00 of every $2.00 deducted.

2. State and county governments contribute a "Colorado Supplement" (CS) in the amount of $17.20. The state contributes 80% of this and the county the remaining 20% or $3.44. This supplement is part of the state/county assistance program called "Aid to the Needy Disabled" (AND).

3. SSA has a program of disability insurance (DI) benefits. To be eligible a worker must have enough work credits (at least 18 months) and be disabled for at least twelve months.

4. Workman's Compensation Insurance provides income and medical coverage for a worker injured on the job. If an individual receives SSA-DI Benefits his Workman's Compensation income is cut 50%.

5. Colorado Vocational Rehabilitation has a variety of programs which are geared to help the disabled person become financially independent through employment. They provide vocational fees, tuitions, transportation, temporary living and maintenance payments. If Vocational Rehabilitation payments exceed the maximum level of income, the person is not eligible for SSI and AND.

B. Subsidies: Programs which subsidize specific categories of income such as rent and food.

1. Rent subsidy is administered by the regional and area offices of the HUD and local housing authorities. The low income person pays no more than 25% of his gross income for it.

2. Food Stamps. The cost of a monthly allotment of food stamps is based on the amount of income that remains after all deductions have been made.

C. Homecare Allowance: Payments which are dependent on the level of individual disability and help meet the need for homecare. This is a program to provide completely and permanently disabled people with funds for attendant care. Its maximum of $217.00 per month is paid for entirely through state and county funds. Only recipients of SSI are eligible for homecare allowance.

D. Medical Benefits: Programs which reimburse part or all of medical expenses.

1. Disabled people under age 65 are eligible for Medicare after they have received DI for 24 months. The program consists of hospital insurance and medical insurance used for doctor's fees.

2. Medicaid is a state-administered program primarily financed by the federal government. All persons receiving SSI income are eligible.

Living Situations

If an individual is severely disabled and needs a variety of supportive services he is institutionalized in Colorado. Institutionalization occurs in Ridge State Home and a variety of independent nursing homes. Within the state and independent nursing homes there is little provision for independent living programs. However, deinstitutionalization is a priority within the State Department of Institutions this year.

Atlantis Community Inc., and Galaxy Inc. are two organizations which were created to assist handicapped persons in the transition to independent living. Here disabled people live together in a cluster of apartments. There is a pool of attendants and counselors. Also there are disabled persons who live in separate apartment complexes but who also have access to the services of the Atlantis Community.

Transportation

In Colorado provision for transportation for disabled persons is sporadic and unsystematic. Primary services are found in the metropolitan areas such as Denver. Various rural areas occasionally have small vans which are run by individual agencies. There is no coordination or pooling of transportation between the different systems or agencies.

The Regional Transportation District (RTD) of the Denver Metropolitan area provides a small "Handi-ride" system. These are small vans which provide service on an on-call basis. Currently there are plans to make the entire fixed route transportation system accessible to the disabled through the installation of lifts.

Amo-cab is a private profit-making corporation. They use small vans with lifts to provide transportation and charge $18.00 round trip fare within the Denver city limits. Funds from third party reimbursements such as the State Department of Rehabilitation and private insurance companies are utilized.

I6-B2 funds, out of Urban Mass Transit Authority (UMTA) are also used to buy small vans with lifts for feeder systems. They provide transporation for disabled people to arrive at main transportation systems.

Another transportation system in Denver is called "Instead." This is a call/response system which provides transportation for the elderly and the handicapped.

Legal Aspects

Attempts to involve the disabled population in the mainstream of governmental programs and services can be seen in the following efforts:

1. The implementation of a protection and advocacy system for developmentally disabled persons--1977.

2. The Civil Rights Bill for the Physically Handicapped (HB 1425)--1977.

3. The Architectural Barriers Law (HB 1125)--1975.

4. The Handicapped Children's Act (HB 1164)--1973.

5. The White Cane Act--1971.

6. The Architectural Barrier Act of 1968. (PL 90-480)

The State Personnel Board, in the last four months, has been working with the State Personnel Advisory Committee to include the handicapped within the state personnel system. The rules and regulations of the state personnel system have been changed to include both physically and mentally handicapped citizens.

To insure further movement in independent living for the handicapped the Governor's Council on the Handicapped was created in Colorado. Its goals are to serve as an advocate and a planning and coordinating body for the concerns of the disabled. This umbrella council is composed of members from the Governor's Advisory Council on the Physically Handicapped, the Mental Health Advisory Council, Special Education Advisory Committee and the Advisory Council on Developmental Disabilities. In obtaining an independent life in Colorado there are many constraints. However, a collaborative relationship with disabled groups and various public and private agencies will serve to assist the disabled citizens of Colorado in their quest for independence.

Independent Living Programs

By Judy Heumann
Deputy Director, Center for Independent Living,
Berkeley, California.

How one who is severely disabled achieves the goal of independence has been a major problem. The lack of appropriate support systems forces severely disabled individuals to remain with their parents or in some form of institutional setting. There are many resulting problems. Persons who are severely disabled frequently fail to view themselves as adults who can take on major responsibility for determining their own life style. This affects one's ability to be able to make independent decisions and results in the adult remaining in a childlike state. Children need greater attention, take less responsibility for themselves or the effects on them from their surrounding environment. Most importantly, children rely on other individuals in the active labor force for the major decisions determining their lifestyle and choices.

The issue of economics is critical to the discussion of independent living programs. If the federal and state governments in the United States persist in failing to recognize the importance of this issue, many disabled individuals will never be able to achieve independence. There is a critical need for the government to do away with the disincentives that have plagued us for so many years. Severely disabled individuals have legitimate additional expenses that must be assumed by the government--there is no way to get around this issue. Persons who need personal care must have the funds to hire people to take care of these needs. Currently, the placing of individuals with these needs in institutions has been viewed as an acceptable solution to this problem. In the eyes of independent disabled individuals this approach is an abysmal failure. I hate to have to argue that from an economic perspective it is cheaper to place an individual outside of the institution. While this is true, I believe we should be discussing this issue on humanitarian rather than economic grounds. If people with disabilities are viewed as important by the people of this country, then the government representing the people must truly assist us in taking our rightful place in society by providing us with money and services that will enable us to achieve these goals.

California's economic program for people who are disabled is the most advanced in the country. But it too falls far short of what our needs are. California supplements the federal SSI program. It additionally has a program called Homemaker/Chore which gives money to persons who are poor and disabled and have personal care needs they cannot take care of themselves. The Medi-Cal program while not being as extensive as is needed is better than in most states.

Obviously there needs to be a careful review of the priorities of our country. Disabled people have the right to support and basic life services. These rights should not be taken away if we enter active employment. Our financial earnings from employment should be taxed as all other persons are taxed. But they should not cost us our basic support benefits.

At CIL in Berkeley, we have been successful in developing an integrated service delivery model. One of the primary reasons for our success is the fact that disabled people control the program. At CIL we make up at least 75% of the Board and 48% of the staff. A non-disabled individual will never be chief executive officer of CIL. The primary deliverers of our services must be disabled people. We act as peers, role models, people who understand the issues because we have personal experience. Non-disabled people can never understand as deeply as we do the needs for independent living. Non-disabled people have controlled our lives without our input and have held us back; now we must take the driver's seat.

The reason why independent living programs in California are proving as successful as they are is in large part due to the economic base provided substantially by the State. We have been able to establish service centers that can begin to provide disabled individuals the life support systems necessary for survival in their communities. The disabled individual has funds to pay for a substantial amount of his personal care needs. This means we in CIL can assist a person in making the transition from parents' home or the institution into the community because he or she can now pay an individual to help with dressing, showering, getting into a wheelchair, shopping, cooking and cleaning. These are basic, basic needs. The 14 independent living programs in California all have components which recruit people to act as attendants to the disabled individual. In all cases the disabled individual hires the attendant. The service center acts as a screening agent and in some cases provides training for the attendants. This might appear to be of insignificant importance. However, to us it is probably one of the most major ingredients for independent living. This program enables people to learn to make decisions they have never had to make before. Many of these decisions are fundamental to a person achieving independence.

When CIL began in 1972, organizers had the benefit of being able to review what other groups had done in the past. The review showed the need to set up a program not based on the medical label an individual had but rather on the similar needs of people who are disabled. CIL started as a coalition of physically disabled and blind people providing primary attendant referral, reader referral, and advocacy services. This model enabled CIL to have physically disabled and blind people on our Board of Directors, as staff, and as clients. Today we provide services not only to the physically disabled and blind, but also to the elderly and the deaf. We are beginning to provide services in the area of counseling, benefit programs, and legal advocacy for parents and children, and hope over

the next few years that the needs of parents and disabled children can be better met by our program. We also hope over the next few years to be able to meet more of the needs of persons who are moderately to severely retarded. All these we believe we are capable of doing if adequate funds are available.

Independent living programs are basically a new phenomenon. In Berkeley's CIL and in other centers for independent living around the country, we are instilling a pride and productivity among disabled individuals that no other governmental program has been able to do. We attempt to deal with the individual's total being, not with one portion. Until this concept is understood, accepted, and validated through the giving of substantial dollars, these programs will remain tottering at the brink of continual economic obliteration. Currently, we are all funded with what many of us call soft money. Programs are given short term money to demonstrate the effectiveness of services. Even when the program is demonstrating itself to be successful, we are not assured of continued monies. A substantial amount of time must be spent raising funds. CIL in Berkeley is currently funded by at least 25 different sources--none of which are guaranteed for continuation. The frustration that this produces is needless. Independent living must be recognized and supported. Governmental units must begin to do cooperative planning which enables people and programs to be viewed as a whole and which allows for funds to flow to programs that work.

Independent living programs have formed a coalition in California. We will be attempting to form a national coalition of independent living programs over the next year. Politically and economically we believe this is critical. We must maintain the integrity of our programs. Yet we know we cannot survive nor continue to grow as we need to without governmental support. This is in part our dilemma. We can confront it.

CHECKLIST FOR DEVELOPING INDEPENDENT LIVING PROJECTS

by Frederick Fay, Ph.D.*

I. Review literature on other centers for independent living.

II. Develop nucleus of committed people who are willing to work.

A. Develop selection criteria for board, officers, and advisory committee (consumer majority? provider support? abilities? disability representation? interest? commitment? fiscal management skills?)

B. Determine initial officers (President, Clerk, Treasurer . . .)

C. Identify and involve potential members for Board of Directors and Advisory Committees.

1. Representatives of key consumer constituencies (National Paraplegia Foundation, National Association of the Physically Handicapped, National Association of the Deaf, Paralyzed Veterans of America, American Council of the Blind, Disabled in Action, and/or other consumer organizations).

2. Representatives of provider organizations (State Departments of Vocational Rehabilitation, Medicaid, Social Services, Regional Rehabilitation Research and Training Center, state or local housing authorities, area rehabilitation facilities, Easter Seal Society, and/or other service providers).

III. Discuss and agree on the center for independent living's program philosophy, purposes and target population.

A. Develop written preliminary program description

B. Interest and involve broad base of support

IV. Select and develop an appropriate organization structure for carrying out the center's purposes.

A. Review state and federal laws on incorporation and tax status of organizations (e.g., 501(c)3 vs. 501(c)4)

B. Prepare the center's articles of incorporation and by-laws. Some of the areas by-laws should cover are:

* Frederick Fay et al. The BCIL Report, edited by Peter Reich. Boston: Regional Medical Rehabilitation Research and Training Center No. 7, Tufts, July 1977.

1. name of the organization

2. principal office location

3. applicable definitions

4. fiscal issues

5. purposes of the organization

6. leadership responsibilities

7. membership responsibilities

8. process for calling meetings

9. process for board and/or membership nominations, elections, voting, resignations, suspension and removal

10. authority to enter into financial agreements

11. personal liability

12. process for amending by-laws

C. Submit organizational papers to appropriate authorities for incorporation, tax status, and employee identification number

D. Affiliate with state coalition or national organization

V. Establish short and long term goals and objectives for the center (one, three and five year plans)

A. Determine what other service organizations in the area provide adequately.

B. Determine which services the center will advocate for and which it will provide itself:

Activities of daily living, Architectural barriers/barrier free design, Attendant services, Chore services, Coalition development communications, Community organization, Consumer affairs information, Economic support services, Educational liaison, Employment services, Equipment repair, Home health aide (Fiscal conduit services), Homemaker, Housing development and adaptation, Independent living training, Information services, Legal services, Lobbying, Life support services, Medical services, Mobility skills, Outreach and Recruitment, Personal care assistants (recruitment, selection, training), Public relations/education, Recreation, Rehabilitation services, Sex education, Social services/State agency liaison, Transportation, Vocational liaison.

C. Determine funding sources for each high priority service objective. To pay for program services, develop fundable proposals and contracts with private foundations and public agencies. Some of the many options to consider include:

a. individuals
b. private sector (foundations, civic groups)
c. State Vocational Rehabilitation Agency
d. State Housing Finance Agency
e. City Housing Authority
f. Department of Community Affairs
g. Department of Housing and Urban Development
h. Rehabilitation Services Administration
i. Veteran's Administration
j. Department of Public Health
k. Bureau of Developmental Disabilities
l. Department of Labor-Comprehensive Employment Training Act
m. CETA (10)
n. Department of Public Welfare
   1. Medicaid (Title XIX)
   2. Social Services (Title XX)
o. Rehabilitation Research and Training Centers
p. Department of Health, Education and Welfare

D. Secure adequate start-up funds

VI. Develop a comprehensive written program plan to meet the center's advocacy and service objectives. This plan should include a description for proposed implementation describing:

A. Priority activities to be undertaken.

B. Persons responsible for carrying out activities (board, committees, executive directors, staff volunteers).

C. Methods used in carrying out activities

D. Location of implementation of activities.

E. Anticipated time duration of activities.

VII. Draw up a budget for the center's comprehensive program plan and organizational operating costs. Make cost projections for the long term plans (three and five year plans).

VIII. Develop and implement a management system to administer the center's plan. Systems to provide accountability should be <u>in writing</u> and should include:

A. Program Content

1. internal record keeping system (data collection) on program utilization
2. a process to prepare external program reports at appropriate times
3. calculations of specific program costs
4. evaluation processes to measure program effectiveness and growth
5. standards for quality service
6. written program descriptions
7. an operational planning process
8. geographical scope of program

B. Program Participant

1. confidentiality protection
2. standard means to periodically review client policies
3. program eligibility criteria
4. standardized forms
5. efficient application admission and graduation procedures
6. measures of performance
7. objectives of participation

C. Fiscal Controls

1. accounting procedures with back-up information on cash receipts, cash disbursements, payroll, closing procedures, budgets, etc.
2. use of standard report forms
3. annual audit by certified persons
4. a control system for making and receiving payments
5. a plan to correct deficiencies
6. a plan to seek continuing financial support (grant, fee for services, etc.)

D. Facility Operations

1. appropriate site location
2. costs to occupy
3. signed lease
4. office procedures regarding correspondence, hours, absences
5. inventory of all equipment
6. building safety and appropriate insurance

E. Personnel Policies

1. hiring practices
2. benefits plan
3. assurance of compliance with federal and state laws
4. job descriptions
5. job evaluations
6. appropriate supportive equipment
7. staff training
8. system to measure job performance
9. staff reporting
10. salary and pension plans

IX. Develop an assessment system to measure progress toward objectives

A. Review at least annually

B. Prepare an annual report

X. Select effective staff

ANNOTATED BIBLIOGRAPHY

American Society of Landscape Architects Foundation. Barrier Free Site Design. Washington D.C.: U.S. Government Printing Office, 1974: 82 p.

This reports results of research conducted by the American Society of Landscape Architects Foundation and sponsored by HUD, Office of Policy Development and Research. Aspects of barrier free design, including federal and local legislation, costs, architectural considerations, and information sources, are discussed.

Arneson, Kathaleen. "Residential Choices and the Handicapped," American Rehabilitation 2(1); Sept-Oct, 1976: 25-29.

Myths and assumptions related to housing for the handicapped are discussed. The national character of the housing issue and the need for a national policy on housing for the handicapped is emphasized. Selected recommendations of the National Conference on Housing and the Handicapped (Sept. 1974) are listed and suggestions for the future are proposed.

Baker, M., Fischetti, M.A., Williams, L.A. and Young, E.M. State and Local Efforts to Eliminate Architectural Barriers to the Handicapped. Washington, D.C.: National League of Cities, Department of Urban Studies, 1974.

In response to questionnaires sent to 379 cities and towns and to 272 counties, only 95 cities and 42 counties reported local efforts to eliminate barriers.

Barrett, Linda W. Legislative Review of the Specific Provisions for Priority to Individuals with Most Severe Handicaps and the Individualized Written Rehabilitation Program. Berkeley Planning Associates, September 1975: 32 p.

Review of the provisions of the Rehabilitation Act of 1973 relevant to priority to the severely handicapped (IMSH) and for implementation of the individualized written rehabilitation program (IWRP). The review covers the legislative history and intent, and the RSA Regulations and Program Guides relevant to the IWRP and the IMSH. In an addendum to the report, Barrett reviews the historical background of the Rehabilitation Act of 1973.

Berkeley Planning Associates (BPA). Vocational Rehabilitation Program Evaluation Standards: A Critique of the State of the Art. 7 January 1977: 177 p. RSA Contract # 105-76-4116.

A review of developments to date in program evaluation standards for vocational rehabilitation services, including an overview of analytical work in the development of standards, a report on the

impact of the current standards in the state vocational rehabilitation issues related to refinement of the standards. Among the issues are: alternative uses of standards in service programs, the problem of defining severity of disability, and problems of reporting and measurement in the existing standards system.

Brewer, Garry D. and Kakalik, James S. Improving Services to Handicapped children, Summary and Recommendations. Santa Monica, California: Rand, May 1974. R-1401-HEW.

This is the summary volume on Rand's study of services provided for the more than 9 million mentally or physically handicapped children and youth in the United States. The Rand study which focused on hearing and vision handicapped children, included interviews with 77 families of such children. The study found that many youth are not receiving services or are receiving the wrong services. There are serious gaps in services offered; information is insufficient, control is inadequate, and the resources devoted to these youth's needs are insufficient.

Policy recommendations made include increasing resources, expanding vocational rehabilitation programs, and conducting research and evaluation of services. Rand argues that the majority of the recommendations, if adopted, would yield benefits that exceed their costs.

Center for Independent Living, Berkeley, California. Report of the State of the Art Conference, Center for Independent Living, October 21-23, 1975. RSA Grant 45-P-45484/9-01.

This report contains a listing of all the papers presented at the first conference on the independent living movement; it was sponsored by Berkeley CIL under a grant from RSA. The five conference papers reproduced in the report volume are:

"The Psychology of Disability," by Carolyn L. Vash, Ph.D.
"CIL History," by Hale Zukas
"The Role of the State VR Agency," by Donald E. Galvin
"Progressive Inclusion, An Approach to Mainstreaming," by Ralph E. Baird
"Independent Living for Individuals with 'Severe Disabilities,' The Federal Outlook," by Frederick A. Fay, Ph.D.

In addition, the conference papers listed below are available from CIL:

"Crips Lib--An Overview of Legal Issues," by Jack Actenberg
"Programs and Expenditures for the Severely Disabled," by Monroe Berkowitz
"Medical Aspects of Disability with a View to Independent Living," by Sheldon Berrol, M.D. and Edna Brean, R.N.
"Legislation, Research and Programs Concerning Housing for Handicapped People in Belgium, Canada, the Federal Republic of Germany, Finland, France, Hong Kong, The Netherlands, Norway and Sweden," by Barbara Duncan

"Independent Living Arrangements for Severely Physically Disabled Persons," by Lex Frieden
"A Model Sheltered Workshop," by Frank D. Gentile
"On-Site Training Program for Professionals Working with People Who Have Severe Disabilities," by Peter Leech, M.S.W.
"Systems Approach and the Physically Unable," by Wallace Motloch, C.O.
"Transportation for the Mobility Handicapped," by Thomas C. O'Brien
"The Three R's of Disabled Consumerism," by Daniel A. Poling II
"Private Industry and the Vocational Rehabilitation Process," by Richard J. Randles
"A New Kid in Town," by Phillip Hatlin
"Center for Independent Living in New York--A Residential Center for the Elderly Blind," by Douglas Inkster
"Sexuality and Independent Living Skills," by Neil Jacobson
"Legal Services by the Disabled for the Disabled," by Debbie Kaplan
"The Disabled Students Programs in the College and University Setting," by Kent Kloepping, Ed.D.
"Independent Living and the State Agency for the Blind--The State of the Art," by Joseph Kohn
"The Impact of Litigation on De-Institutionalization: A Movement Toward Independent Living for the Mentally Disabled," by Kathleen Ursin

Cole, J.A., Holden, B.L. and Frieden, Lex M. The New Options Project: A Live-In Program to Foster Social Adaptive Skills. Paper presented at scientific sessions of 53rd Annual Session of the American Congress of Rehabilitation Medicine and the 38th Annual Assembly of the American Academy of Physical Medicine and Rehabilitation, November 7-12, 1976 in San Diego.

This paper describes a six week transitional program, sponsored by the Texas Institute for Rehabilitation and Research, to assist severely handicapped individuals in acquiring necessary skills for living in diversified settings.

Cole, J.A. and Frieden, Lex. Transitional Living: A Program Fostering Community Integration of Severely Physically Handicapped Persons. Houston: Texas Institute for Rehabilitation and Research, June 1977. Interim Report on RSA Project Grant #13P57889/6-01 (RT 4).

This report describes progress on the New Options project in Houston which is a model transitional living program housed in TIRR's Maximum Independence Center. Two primary types of research are conducted in the transitional living project: 1) examines the development and evolution of the project from a holistic anthropological perspective; 2) employs a longitudinal multimeasure design with control groups to evaluate the effects of the program on participants' behavior, attitudes, and information base. In this report, Cole and Frieden describe the study design, and progress to date in New Options.

Council of State Administrators of Vocational Rehabilitation (CSAVR). "Independent Living Rehabilitation Survey Results" CSAVR Memorandum CSA77-40, 4 August 1977: 6 p. attachment.

Results of an in-depth survey of the state vocational rehabilitation directors by their organization in February 1977 as to their concepts of ILR.

Collignon, Frederick C., Dodson, Richard, and Skaburskis, Andrejs. An Evaluation of the Costs and Effectiveness of Vocational Rehabilitation Service Strategies for Individuals Most Severely Handicapped, (IMSH). Berkeley: Berkeley Planning Associates, May 1975. Subcontract to the Urban Institute, Comprehensive Needs Study HEW-SRS-74-54-3.

Data on the characteristics and expenditures for various kinds of services are analyzed for the individual cases closed in the Michigan and Washington vocational rehabilitation programs in FY 74. The definition of Individuals Most Severely Handicapped (IMSH) was based on a classification system of primary diagnostic codes used in the Federal Vocational Rehabilitation R-300 records. It appears that severely disabled individuals are not more difficult to rehabilitate successfully for employment than other vocational rehabilitation clients, although closure is more costly. The analysis revealed that the combination of certain degrees of old age, and lack of education, with being female and non-white were more predictive of difficulty than the type and severity of impairment.

"Eliminating Barriers," American Rehabilitation 1(2); Nov-Dec, 1975. 32.

An on-going community project to make Chicago more "accessible" through the elimination of transportation and architectural barriers is described. The project, "Access Chicago," began as a demonstration project by the Northwestern Medical Rehabilitation Research and Training Center.

Everett, Todd H. and Collignon, Frederick. Cost and Policy Considerations in Improving the Capacity for Independent Living of the Most Severely Handicapped. Berkeley: Berkeley Planning Associates, May 1975.

The results of a study conducted to evaluate the cost and impact of services to the most severely handicapped individuals are reported. The service areas considered by this study include: transportation, relocation, housing, medical care and employment. Policy design, goals, and recommendations are also discussed.

Farber, Douglas A. Housing and Related Services for Exceptional Persons: A Source Book. Monticello, Ill.: Council for Planning Libraries, 1973: 176 p.

This book contains information about the characteristics of the aged, physically handicapped and the mentally retarded, descriptions of existing programs and facilities, a discussion of models of optimum care and an analysis of the constraints interfering with the improvement of present conditions. Lists of associations, foundations, federal agencies, research institutions and periodicals, and a bibliography of 796 indexed items are also included.

Fay, Frederick. Housing Alternatives for Individuals with Spinal Cord Injury. Boston: Tufts Rehabilitation Research and Training Center, 1974: 37 p.

Summarizes problems of housing for spinal cord injured persons and presents two housing alternatives: (1) total accessibility in all residences for individual living and (2) accessible group residences. Five group housing residences reflecting five different approaches are examined, and efforts being made to eliminate architectural barriers are reported.

Fay, Frederick, et al. The BCIL Report, edited by Peter Reich. Boston: Regional Medical Rehabilitation Research and Training Center No. 7, Tufts, July 1977.

A summary of the first years of the Boston Center for Independent Living, Inc., a transitional living program for persons with physical disabilities. Includes a "How To" checklist of items to consider if developing a center for independent living.

Fink, Charlotte, Manus, Muriel R. and Manus, Gerald I. Housing for Disabled Persons: Annotated Bibliography. New York: United Cerebral Palsy Association, 1975: 19 p.

Forty journal articles and books are included in an annotated list; sixty additional references are listed.

Frieden, Lex. "Independent Living Arrangements for the Severely Disabled," Report on the State of the Art Conference, Center for Independent Living. October 21-23, 1975. RSA Grant 45-P-45484/9-01.

This article discusses the philosophical and ideological basis of independent living arrangements. Physical and social aspects of the housing facility are also considered, as are life support systems (attendant care) and the managerial skills necessary for attendant affairs. The author also gives examples of various housing modes and offers a two-dimensional analysis of these programs. Funding, accountability, social relationships and community relationships are briefly discussed.

George Washington University. Rehabilitation Research and Training Center. Development of Modern Vocational Objectives For Severely Disabled Homebound Persons: Remote Computer Programming, Microfilm Equipment Operations, and Data Entry Processes. Washington, D.C.: 1974: 235 p.

The results of a four-year Research and Demonstration project on the development of new training and employment techniques are described. The functional relationships between the worker and information-handling tools and processes and the increased productivity resulting from low cost adaptation of these tools are presented. Three companies formed, owned and managed by homebound disabled persons as a result of this project, are summarized. The possibilities of the self-employment for the disabled and the utilization of the project results by other rehabilitation programs are examined.

Jones, F. Ron. Cost Analysis of Alternative Transportation Systems for the Handicapped. Berkeley: Institute of Urban and Regional Development, University of California, 1975. Working paper No. 256.

There are approximately 7,600,000 persons in the U.S. who suffer chronic mobility limitations as a result of physical disabilities. This paper discusses various ways of improving the mobility of these individuals, and analyzes the impact and cost of each alternative. The alternatives discussed are: curb modification; wheelchairs; modified automobiles and vans; fixed-route transit systems; demand-responsive systems; and mobility counseling.

Lassen, Peter L. Barrier Free Design: A Selected Bibliography. Washington, D.C.: Paralyzed Veterans of America, Inc., 1973: 96 p.

References under 22 headings are included in this annotated bibliography on designing for full accessibility. See also the 1975 supplement which includes references for 1973-1975.

Laurie, Gini. Housing and Home Service for the Disabled: Guidelines and Experiences in Independent Living. New York: Harper and Row, 1977.

Comprehensive guidebook to housing and home services. Covers adaptations for kitchens and bathrooms; attendant care; living arrangements and methods of finance; cost information; and applicable legislation, standards, codes and policy. The first volume to cover both aids to daily living and the new independent living organizations developing around the country.

Lewis, Sylvia. "The Disabled Are Tired of Being Pushed Around," Planning 43(6), July 1977: 9-13.

Lewis reviews recent advances in creating barrier-free environments, citing the Center for Independent Living in Berkeley as "perhaps the nation's most comprehensive service organization for the disabled" and noting that organization's success in eliminating barriers in the community. The article provides an analysis of recent programs to improve the built environment, and discusses problems in the implementation of the Rehabilitation Act of 1973, including Section 504 and the Architectural and Transportation Barriers Compliance Board.

Loshin, Ronald S. and Collignon, Frederick C. Discussion and Survey of Benefit Cost Studies of Vocational Rehabilitation. Berkeley: Berkeley Planning Associates, 1975, Subcontract to The Urban Institute, Contract No. HEW-SRS-74-54-3.

This study examines the general complexities of applying benefit-cost analysis to vocational rehabilitation, and surveys literature on several significant models of vocational rehabilitation. Particular attention is focused on model components, methods of estimation, data base selections, and benefit-cost ratio results reported.

Motlock, W.M. Mobility for Spinal Cord Impaired Patients. Presented at Conference on Mobility for Spinal Cord Impaired People, National Academy of Science, held at Rancho De Los Amigos, Downey, California, February 1974.

The ambulation system described here is for paraplegics. The author presents transportation systems in terms of modules which represent stages of mobility.

Nau, Louis Y. and Turem, Jerry. "The Comprehensive Needs Study," American Rehabilitation 1(2); 1975: 9-12.

The methodology and major findings of the Comprehensive Needs Study funded by RSA are summarized.

Overby, Charles M. "Will Technology Change Work Living Patterns?" Journal of Rehabilitation 39(6); Nov-Dec, 1973: 18-19, 41.

Potential patterns of work organization which could result from developments in the computer-telecommunication area--namely, taking employment to the immobile--are discussed. The conclusions of a conference concerning new work patterns in an information era held in Ohio in June 1973 are summarized.

Rehab Inc. An Analytical Appraisal of the Definition of Severe Handicap: A Final Report. 1976. Project sponsored by RSA, HEW.

This report, prepared for RSA, reviews the definitional problem, but does not provide closure. Some of the findings reported were: (1) the current RSA classification guidelines are used differently across states; (2) there is need for more training and reliability testing in classifying clients; and (3) not all persons with listed disabilities are severely handicapped with respect to employment, nor are all persons requiring multiple services over long periods of time severely handicapped. In contrast, many people with disabilities not listed in the severe codes, whether alone or in concert with other variables, are rendered severely handicapped with respect to employment (e.g., drug abusers).

The recommendations in this report include: clarification of definitions with emphasis on severely handicapped, not disabled; consistency in applying the definitions; changing and tightening the severity codes and including evidence of a substantial handicap to employment; and revising categories of functional limitations, linking them to job performance and also covering socio-economic and emotional handicaps.

Schmidt, Bruce L. An Alternative Approach to Assessing Client and Social Benefits Resulting From Services Provided by the California Department of Rehabilitation. A working paper written for the California Department of Rehabilitation, 830 K St., Sacramento, Calif. 1976.

Benefit cost analysis of rehabilitation is reviewed in terms of accuracy and resulting implicit and explicit policy. The author presents an alternative mechanism for measuring client gain in not only vocational benefits, but independent living benefits in general.

"Transportation for the Disabled: What is the Government Doing? When? Where? With What?" Accent on Living 20(1); Summer, 1975: 40-42.

Government sponsored programs and organizations focusing on transportation for the disabled are described. The five major programs of the Urban Mass Tranpsortation Administration (UMTA) for aiding mass transit are presented: the Research and Development Program; Operational Demonstration Program; the Capital Assistance Program; the Planning Assistance Program; and the Rural Public Transportation Demonstration Program.

"Travel," Rehabilitation Gazette 17; 1974: 2-11.

Practical suggestions for handicapped travelers are presented in a series of short personalized accounts. Special travel agencies and guidebooks are listed.

Turem, Jerry S., "Testimony Prepared for the Subcommittee on Handicapped, Committee on Labor and Public Welfare, United States Senate." Washington, D.C.: The Urban Institute, March 21, 1976.

Testimony before the Senate subcommittee by Jerry S. Turem, Ph.D., Director of the Comprehensive Needs Study authorized under Section 130 of the Rehabilitation Act of 1973. The testimony outlines the approach to the study, the participants in the study, some key findings and policy interpretations.

Turem, Jerry and Nau, Louis Y. "Comprehensive Needs Study, Part II," American Rehabilitation 1(4); Mar-Apr, 1976: 6-9.

The results of the Comprehensive Needs Study which focused on ILR--architectural barriers, transportation problems, equipment needs, long term care, income and health transfers, residential mobility, isolation, recreation--are briefly discussed. Several programmatic options for making services accessible to the handicapped are proposed. Commitment of financial support is identified as the primary ingredient currently needed to initiate a program of independent living.

US Architectural and Transportation Barriers Compliance Board. Freedom of Choice: Report to the President and to the Congress on Housing Needs of Handicapped Individuals. Washington, D.C.: 1975. 2 vols.

The national Public Hearing on Housing for Handicapped Individuals conducted by the Board in Chicago on June 9 and 10, 1975 is summarized in Volume I. Documentation of existing federal legislation and programs affecting housing for the disabled, and recommendations for actions essential to a national commitment to meet the housing needs of the disabled are also summarized. Viewpoints, observations and recommendations of the hearing participants are categorized under 19 major topics. A transcript of the oral and written testimony presented at the hearing is contained in Volume II.

US Department of Health, Education and Welfare, Office for Handicapped Individuals. A Summary of Selected Legislation Relating to the Handicapped, 1975-76. Washington, D.C.: May 1977.

This booklet contains brief synopses of legislation enacted by the 94th Congress affecting physically and mentally handicapped persons. It is designed to help program planners, students and interested citizens gain insight into the output of federal policy formulation. The laws summarized authorize programs with varied objectives benefiting handicapped persons.

Single copies are available from the Office for Handicapped Individuals, 338D South Portal Building, 200 Independent Avenue, S.W., Washington, D.C. 20201. Limited copies of the 1971, 1972 and 1974 publications are also available from that office.

US Department of Health Education and Welfare, Rehabilitation Services Administration. Rehabilitation Services Manual. Washington, D.C.: 15 October 1975.

Chapter 25 of this manual provides guidelines to state vocational rehabilitation agencies for the involvement of consumers and consumer representatives of the rehabilitation service delivery system. The guidelines outline a variety of methods for utilizing persons with disabilities and their self-help organizations in the planning, delivery and evaluation of rehabilitation programs.

US Department of Transportation. Transportation for the Handicapped: Selected References. Bibliographic List No. 8. Washington, D.C.: 1975: 39 p.

This updated version of the Department's Bibliographic List No. 1 (169) on transportation for the handicapped is arranged according to subject categories, with individual, corporate source and geographic indices. 225 selected journal articles, papers and reports are included in this partially annotated listing on transportation mobility and aids for the physically handicapped and elderly.

The Urban Institute. Report of the Comprehensive Service Needs Study. Washington, D.C.: Rehabilitation Services Administration, June 1975: 854 p. Contract #HEW 100-74-0309.

In the Rehabilitation Act of 1973, Section 130, Congress called for a comprehensive study of service needs of the most severely disabled individuals. The study was conducted by The Urban Institute and a consortium of other firms and individuals. During the study, extensive interviews were conducted with approximately 900 individuals who had been chosen form vocational rehabilitation agencies because of severity of disability. In addition, approximately 300 severely disabled individuals not served by vocational rehabilitation were contacted through CMRCs. The report on the study results details a number of problem areas for the disabled: architectural barriers, transportation, employment, and social interaction. In addition, there is discussion of special problems of mental retardation, of the blind and visually impaired, the deaf and the mentally ill. Provision of rehabilitation services is reviewed, based on a survey of providers. Key policy recommendations are offered concerning: definition of the eligible population, transportation, employment and labor force participation, long-term care, health coverage, income maintenance, coordination of HEW programs, consumer involvement, and financing.

The Urban Institute. First Year Report on Section 130 Demonstration Projects. Washington, D.C.: July 1976.

There were six demonstration projects funded as a part of the Comprehensive Needs Study as a result of the Rehabilitation Act of 1973. This first year report describes the background and purpose of the six demonstration projects and the initial population served, and presents an analysis of the data available at the end of the start-up year.

Each project in the series illuminates more than one issue, some with greater emphasis than others. Each project highlights a possible service delivery model for establishment of an independent living program. Each project will demonstrate its ability to organi e and meet objectives of an ILR-type program for persons not usually served in a state vocational rehabilitation program. Each project will be developing information on cost and manpower implications.

More detailed information is available in the individual reports of the five separate projects that remain: University of Washington, Department of Rehabilitation Medicine, Seattle; New York State Agency and the Institute for Rehabilitation Medicine (IRM); Utah Project, Utah State VR agency, Salt Lake City; Texas Blind Project, San Antonio, Texas; Center for Independent Living, Berkeley, California.

Van Vechten, Doris and Pless, I. Barry. "Housing and Transportation: Twin Barriers to Independence," Rehabilitation Literature 37(7); July, 1976: 202-207, 221.

Results of a community wide survey conducted by the Genesee (N.Y.) Region Health Planning Council to identify the housing and transportation needs of the disabled are discussed. The data analysis is focused on 261 individuals, aged 20-50 years, with major physical disabilities.

The White House Conference on Handicapped Individuals, Delegate Workbook. Workshop VII, Special Concerns (1) Severely Disabled: Service Delivery; Housing. Washington, D.C.: May 22-27, 1977.

The major task of delegates at the Conference was to discuss merits and implications of special interests and concerns. To assist in this process, a set of delegate workbooks were prepared. This workbook on "Special Concerns," relating to severely disabled service delivery and housing, contains many work pages where delegates were asked to rank by priority, for policy recommendations, a variety of service-related issues. These results are to be tabulated. In addition, the workbook itself provides an extensive list of policy issues pertinent to the topic of independent living.

The White House Conference on Handicapped Individuals. Volume One: Awareness Papers. Washington, D.C.: May 23-30, 1977.

A reader of papers prepared for delegates and observers of the White House Conference. The papers are on health, social, economic, educational and special concerns of the handicapped. Of particular relevance to independent living are:

"Architectural Accessibility," by R.L. Mace, p. 147
"Transportation Accessibility," by H.F. Goodkin, p. 167
"Economic Concerns of Handicapped Individuals," by Berkowitz et al., p. 217
"Problems of Severely and Multiply Handicapped," by F.Fay, p. 287
"Community and Residential Based Housing," by L. Friedan, p. 349
"Service Delivery Systems," by C.W. Hoehne (P. Hoffman, ed.), p. 369
"Civil Rights and Addendum," by L.T. Rigdon, p. 393